

This is the eleventh in a periodic series of special reports on federal policies governing the financing and provision of services for persons with developmental disabilities. The general aim of these Federal Funding Inquiry reports is to explore, in detail, the implications of new and emerging federal assistance programs and policies as they affect citizens with developmental disabilities.

**FEDERAL MEDICAID POLICIES AND
SERVICES TO AMERICANS
WITH DEVELOPMENTAL DISABILITIES:
CRITICAL ISSUES - DIFFICULT CHOICES**

by

**Robert M. Gettings
Gary A. Smith**

**National Association of State Mental
Retardation Program Directors, Inc.
113 Oronoco Street
Alexandria, Virginia 22314**

January 1989

**Prepared by the
National Association of State
Mental Retardation Program Directors, Inc.
113 Oronoco Street
Alexandria, Virginia 22314**

Price: \$20 per copy

**Copies may be ordered by
contacting the Association at
(703) 683-4202**

TABLE OF CONTENTS

Preface	i
I. Introduction	1
II. The Evolution of Federal Medicaid Policies Affecting Developmental Disabilities Services	4
A. The Medicaid Program	4
B. Medicaid Policies and Developmental Disabilities Services	6
C. The Evolving Role of Medicaid in MR/DD Services	10
D. Conclusion	22
III. Medicaid's Role in Financing Developmental Disabilities Services: The Deepening Entanglement	24
A. Transformation in Service Delivery Systems	24
B. Medicaid Financing: Its Expanding Role in State Service Delivery Systems	28
C. Critical Trends in the Use of Medicaid Dollars	31
D. Conclusion	40
IV. Proposals to Reform Medicaid Policies	42
A. Chafee/Florio	42
B. The Waxman Proposal	47
C. The ASPE/HHS Proposal	55
D. Reforming the Waiver Program	60
E. Incrementalism	62
F. Summary	63
V. Critical Medicaid Reform Issues	64
A. Eligibility for Medicaid Services	64
B. Medicaid Coverage of Community Services	71
C. Regulating and Monitoring Medicaid-Funded Community Services	80
D. Limitations on Medicaid Payments	87
E. ICF/MR Policies	94
F. Appropriate Placement of Persons with Developmental Disabilities	102
G. Employee Protections	107
H. Paying for Services	112
I. Medicaid Administrative Responsibilities	117
J. Summary	119
VI. Critical Issues - Difficult Choices	120
A. Critical Issues/Difficult Choices	120
B. Prognosis	128
C. Conclusion	130
 <u>Appendices</u>	
Appendix A: The Chafee/Florio Legislation	A-1
A. Legislative History	A-1
B. Description of the Legislation	A-2
C. Commentary on the Legislation	A-14
D. Fiscal Ramifications	A-18

Appendix B: The Waxman Legislation	B-1
A. Legislative History	B-1
B. Basic Structure of the Waxman Bill	B-2
C. Commentary on H.R. 5233	B-10
D. Estimated Fiscal Impact of H.R. 5233	B-20
Appendix C: The ASPE/HHS Medicaid Reform Proposal	C-1
A. Introduction	C-1
B. Basis of the Proposal	C-2
C. Description of the ASPE/HHS Proposal	C-3
D. Commentary on the Proposal	C-11
E. ASPE's Other Reform Options	C-14
F. Conclusion	C-15
Appendix D: The Section 1915(d) Waiver Authority	D-1
A. Background	D-1
B. Description of the Section 1915(D) Waiver Authority	D-2
C. Implications for MR/DD Long-term Care Services	D-3
D. Prognosis	D-4

Charts and Tables

Fig. 1: Average Daily Population of Public Residential Facilities for Persons with Mental Retardation and Developmental Disabilities: 1955 - 1987	25
Fig. 2: Community MR/DD Services Spending: 1977-1986	26
Fig. 3: Financing of State MR/DD Institutions: 1977-1986	28
Fig. 4: Financing of Community MR/DD Services: 1977-1986	29
Fig. 5: Medicaid's Relative Role in Financing Community and Residential Services: 1977-86	30
Fig. 6: Allocation of Medicaid Funds for Persons with Mental Retardation: 1977-1986	33
Fig. 7: Public-Private ICF/MR Beds: 1977-1986	32
Fig. 8: Large v, Small ICF/MR Beds: 1977-1986	34
Fig. 9: State/Federal Medicaid Spending on Behalf of Persons with Developmental Disabilities: 1975-1987	35
Fig. 10: States with HCB Waivers Serving Persons with Developmental Disabilities: 1981-1988	36
Fig. 11: HCB Waiver Expenditures for MR/DD Services: 1982-1987	37
Fig. 12: Developmentally Disabled Recipients of Medicaid Reimbursable Long-Term Care Services: 1975-1987	38
Fig. 13: Public MR/DD Facilities Per Diem Rates: 1977-87	39
Table 1: Estimated Fiscal Impact of H.R.3454 - Congressional Budget Office	A-19
Table 2: H.R. 5233: Estimated Federal Costs	B-20
References	

PREFACE

The impediments to using Medicaid dollars to support specialized services for persons with severe, lifelong disabilities have become increasingly apparent in recent years. As further operational experience has been gained with Medicaid financing of such services, a growing number of state and local officials, providers and consumer representatives have come to the conclusion that present federal policies are out-of-step with the principal aims of the field of developmental disabilities.

In large part, this growing dissatisfaction with federal Medicaid policies is a direct result of the noteworthy shift in program values that has occurred over the past decade. In the past, the values of independence, productivity and community integration that now undergird the delivery of developmental disabilities services were viewed as lofty goals but often impractical, given the societal barriers that faced persons with severe, chronic disabilities. Today, however, we have come to recognize that the real challenge confronting the service system is not to act as "caregivers" but rather to arrange the formal and informal supports necessary to assist each person with developmental disabilities to take his or her own place in the community. Program initiatives in areas such as family support services, supported employment, and integrated community living arrangements have begun to demonstrate that more should be expected of service systems than merely "caregiving."

Current policies governing the utilization of federal Medicaid dollars on behalf of Americans with developmental disabilities are based on laws enacted seventeen years ago. At the time the ICF/MR program was created in late 1971, the primary role of publicly-financed services, in fact, was to furnish "caregiving" in large congregate settings. Broad-based, dynamic systems of community-based services were a dream that many shared but few expected to become a reality in the foreseeable future.

As in many other areas of public policy, during the late 1970s and early 1980s, changes swept across the field of developmental disabilities. These changes not only raised the expectations of consumers and professionals alike, but also led to a growing mismatch between the aims of federal policy and contemporary views regarding the most effective methods of serving persons with developmental disabilities. The ever increasing reliance of the states (and, thus, consumers and service providers) on Medicaid dollars to finance specialized developmental disabilities services created a difficult dilemma: how to change federal policies without creating enormous disruption in the lives of tens of thousands of Americans. In addition, by the early 1980s the secondary effects of the expansion in special education services began to be felt, as thousands of young adults with developmental disabilities exited the school system only to find that services were not available in their communities and were not likely to be available in the near future unless Medicaid laws were radically restructured.

Against this backdrop of increasing frustration with current federal Medicaid policies and a growing backlog of current service needs in nearly every state, proposals have been advanced to change federal policies and, thereby, rectify some or all of these problems. There is no question that the seriousness of the discussions regarding needed policy changes has intensified considerably since Senator Chafee introduced the first version of his Medicaid reform bill in late 1983. Yet, for the most part, the debate thus far has focused primarily on a narrow range of issues that are endemic to the delivery of services to this population — e.g., the relative merits of providing services in large congregate care facilities versus small, integrated community residential settings. While these are public policy issues that need to be debated and resolved, they are not, as too many proponents of both sides of the argument suggest, the only issues and, indeed, may be secondary considerations in shaping the actual development of federal Medicaid reform legislation. Unfortunately, thus far, relatively little

attention has been given to the question of how to structure Medicaid reimbursement for developmental disabilities services that reflect contemporary values and practices within the general framework of the Medicaid program, especially at a time when any further expansion in spending on social entitlement programs is certain to be severely constrained by the overriding political and economic necessity of controlling the federal deficit. Unless a resolution is found to this dilemma, it seems certain that the DD field's frustrations with current Medicaid policies will continue to mount.

This report is divided into three parts. The first three chapters trace the evolution of Medicaid policies governing the financing of specialized services for persons with developmental disabilities. Our aim is to identify the origins of the various limitations of federal policies that have been cited by critics of the program. Chapters IV and V examine, in considerable depth, several noteworthy proposals to reform current Medicaid policies. Our intent is to help the reader gain a better understanding of the implications of these proposals, particularly with regard to several critical dimensions of federal policy affecting services to persons with developmental disabilities. The final chapter attempts to pinpoint the critical issues and difficult choices that must be faced in constructing a more satisfactory set of policies that will allow the field to pursue the positive service delivery initiatives pioneered over the past decade.

The general aim in this report is not to describe an ideal solution to the dilemmas faced by the field of developmental disabilities, or to single out any particular Medicaid reform proposal as a superior alternative. It strikes us as highly unlikely that any solution can be developed that satisfactorily addresses all the objectives and expectations of the various competing interests that will play a role in reshaping current federal policy in this area. Instead, this report's more modest objective is to illuminate, as clearly as possible, the complex set of issues that constitute the existing Medicaid financing dilemma and assess the implications of the various proposals for resolving these problems.

Another of the principal aims of the report is to provide the reader with basic information regarding the current Medicaid program, as it impacts on persons with developmental disabilities, as well as the various proposals that have been offered for reforming it. It is unfortunate, in our opinion, that both opponents and proponents of Medicaid reform legislation too often have attempted to portray the current program, as well as suggestions for altering existing statutory provisions, in overly simplistic terms. The truth is that Medicaid is a highly complex program; and, therefore, if one is serious about making basic modifications in statutory provisions governing the program, it is absolutely essential to understand how it works and why it sometimes thwarts the accomplishment of desired program outcomes. Third grade primers on Medicaid reform issues simply will not suffice for this purpose. Hopefully, the patient reader of this report will be rewarded by a better understanding of the difficulties and potentially feasible options that might be pursued to restructure federal Medicaid policies.

A word of explanation about the perspective of the authors is in order. As the principal staff members of an organization that has played, and hopefully will continue to play, a central role in the national debate over the restructuring of Medicaid policies affecting persons with developmental disabilities, it would be disingenuous on our part to suggest that the analysis provided in this report is totally unaffected by our work on behalf of the Association over the past few years. On the other hand, the opinions contained in the report are those of the authors and do not necessarily reflect the official position of the National Association of State Mental Retardation Program Directors, Inc. or any of its member state agencies. We have attempted to present the issues, as we perceived them, in as even-handed a manner as possible, but have no illusions that other, equally valid, points of view can be advanced. Where the biases of our peculiar experiences and perspectives show through, the challenge to the reader is to reach a defensible alternative conclusion based on the same set of factual realities.

Finally, it would be foolish to predict how or when substantial reform will occur in present federal Medicaid policies that affect services to persons with developmental disabilities. It is clear that the 101st Congress will take up the debate surrounding such policies. If substantial

reform is to occur during the next session of Congress, however, all major parties to the debate -- state administrators, advocates, service providers, consumers and their families, and federal, state, and local policymakers ~ must be properly equipped to understand the dynamics of Medicaid policies. Hopefully, this report will contribute to such an understanding.

Robert M. Gettings
Gary A. Smith

January 1989

CHAPTER I

INTRODUCTION

FEDERAL MEDICAID POLICIES AND SERVICES TO AMERICANS WITH DEVELOPMENTAL DISABILITIES: CRITICAL ISSUES -- DIFFICULT CHOICES

I. INTRODUCTION

Over the past five years, a national consensus has emerged that federal Medicaid policies affecting the delivery of Title XIX-reimbursable services to persons with developmental disabilities need to be reformulated. A new set of policies is needed that recognizes the remarkable and still unfolding transformation that has taken place in developmental disabilities services (i.e., the movement from an institutionally-dominated system — aimed at furnishing comprehensive care in segregated settings ~ to decentralized community-based service networks, emphasizing the coordination of diverse supportive services within the mainstream of community life).

Federal statutory policies regulating the expenditure of Title XIX dollars on behalf of persons with developmental disabilities were adopted nearly twenty years ago and, in many important respects, remain unchanged today. These Medicaid policies stand as a major impediment to the achievement of the critical policy goals of the field. Contemporary standards and practices demand that federal support for specialized developmental disabilities services more fully recognize the diverse array of extended support services that can play important roles in aiding individuals to fully participate in community life. Unfortunately, present policies confuse institutional placement with the achievement of the overarching objectives of service delivery.

The need to reformulate federal Medicaid policies, however, is more than simply a matter of adjusting Title XIX law to reflect contemporary practices. Entire state service delivery systems have been organized around present federal policies. Effective reform of such policies cannot occur by simply sweeping away existing services and programs in favor of new approaches. Furthermore, recent changes in federal policies are having far-reaching repercussions on how individual states manage their developmental disabilities budgets as well as their capacity to address new service demands. Consequently, if Medicaid reform legislation is to meet its intended objectives, these factors must be addressed as well.

While the broad outline of needed changes in federal policies has become increasingly clear, Congress thus far has been unwilling to enact legislation to correct these perceived shortcomings. Instead, substantive reform appears to be snarled in a policy gridlock of competing goals, where each of the major actors (i.e., the Administration, Congress, the states, and other interest groups) expresses overlapping — and sometimes competing — objectives which they are seeking to achieve through reform legislation.

For example, the dilemma posed by the federal budget deficit seems to imply that a reform proposal, if it is to be politically and fiscally viable, cannot trigger a major increase in federal budgetary outlays, at least in comparison with the rate of increase projected under current law. With state budget surpluses now at a twelve-year low point, it is equally clear that a viable reform proposal cannot be predicated on forcing states to accept massive new financial obligations. At the same time, however, a successful reform proposal must acknowledge that there is a tremendous disparity between the number of individuals with severe disabilities who receive federally-assisted long-term care services today and the total number of persons who need specialized DD services; closing this services "gap" is likely to be a very expensive proposition. The key unresolved questions are: to what extent should the

federal government participate in such additional costs and how can legislation be best structured to accomplish this national reform agenda?

Similarly, a sound reform proposal must include a credible strategy for assuring that federally-assisted services meet basic quality standards. Achieving this objective, however, may conflict with the goal of allowing state and local jurisdictions sufficient latitude to design and develop service systems that are both responsive to local circumstances and capable of meeting the diverse and changing needs of persons with developmental disabilities in an effective and efficient manner. MR/DD services are perhaps marked by greater state-to-state variability than any other area of human services, both in terms of system organization and the range and scope of services that are furnished. While some find fault with this diversity, many would argue that the historic leadership role accorded the states in the development of MR/DD services has contributed enormously to fostering innovation and creativity in service delivery. How might this fundamental conflict between proscriptive federal policies and state/local flexibility in the design and management of programs be resolved?

As a consequence of the apparent inability to resolve such underlying conflicts, action on reform legislation has been stymied for several years. While it is impossible to predict the future course of Congressional action, the likelihood is that the current gridlock will persist until a Medicaid reform proposal can be fashioned that satisfactorily reconciles critical ideological values, federal and state roles in the management of service delivery, and fiscal realities. The objective of redirecting federal assistance to emphasize the delivery of supportive services tailored to the needs of individuals and their families, within the context of integrated community-based programs, appears to be a shared goal of most, but not all, of the key actors in the current debate surrounding MR/DD long-term care policy. How to achieve this goal while still satisfying the host of frequently disparate conditions that various interest groups attempt to impose is not nearly as clear.

A new Administration will take office in 1989. The 101st Congress will take up the now five-year old debate regarding the reformulation of Medicaid developmental disabilities policies. There is no doubt that this topic will be the subject of intense controversy. Vastly different solutions have been advanced for resolving the complex web of issues that have emerged concerning present policies. How these various proposals are reconciled will have far-reaching consequences on the lives of Americans with developmental disabilities.

The purpose of this report is to examine, in detail, the key policy issues that must be addressed in crafting a fundamental reformulation of current federal Medicaid policies as they affect services to persons with developmental disabilities. The report is not aimed at defining the "best" reform strategy. Rather, its objective is to illuminate the broad policy issues that must be addressed in the development of a viable reform package.

The report begins in Chapter II with a description of the evolution of federal Medicaid policies as they affect persons with developmental disabilities. Understanding the evolution of these policies will assist the reader in obtaining a firmer grasp of the varied factors that lie at the heart of the deep frustration of the many interest groups that have been calling for statutory reforms.

Chapter III pulls together a wide variety of data to illustrate trends in the utilization of Medicaid dollars on behalf of persons with developmental disabilities. This section provides a baseline of factual information and analysis designed to illustrate the dimensions of Medicaid's role in supporting services to persons with developmental disabilities, the ways in which that role has changed, and how it is evolving under present policies.

Chapter IV describes the principal proposals that have been advanced for addressing these key problems. These proposals are examined critically in terms of their potential programmatic, administrative, and fiscal ramifications. The material in this section is supplemented by several appendices which describe many of the specific proposals and alternatives in greater depth.

Chapter V examines several specific dimensions of present federal policies. Current policies are described along with the unresolved issues associated with each. Various options for addressing these issues are identified and the advantages and disadvantages of each assessed.

Finally, Chapter VI attempts to synthesize the previous materials, in order to isolate the critical choices that must be made in restructuring current federal Medicaid policies. In one fashion or another, the areas discussed in this concluding section constitute the essence of the topics that must be addressed in pinpointing the types of Medicaid policies that will serve the best interests of persons with developmental disabilities during the 1990s. The specific choices that are made in these areas will have enormous consequences — just as the decision in 1971 to establish the Intermediate Care Facility for the Mentally Retarded - has driven state/local service delivery decisions over the past seventeen years.

CHAPTER II

THE EVOLUTION OF FEDERAL MEDICAID POLICIES AFFECTING DEVELOPMENTAL DISABILITIES SERVICES

II. THE EVOLUTION OF FEDERAL MEDICAID POLICIES AFFECTING DEVELOPMENTAL DISABILITIES SERVICES

Over the past several years, there has been a substantial shift in perspective regarding the role of the Medicaid program in supporting services to persons with developmental disabilities. Where once Medicaid funding was regarded as a critical element in fueling the expansion and enhancement of such services, increasingly it has come to be viewed as an impediment to the achievement of key philosophical goals as well as a serious threat to the stability of general state funding for the delivery of MR/DD services. This change in perspective is one of the key factors that has prompted calls for the reform of present Medicaid policies.

In this section, the history of Medicaid financing of services to persons with developmental disabilities and how the two have become progressively intertwined is recounted. To set the context for this discussion, the section begins with a brief review of the often misunderstood nature of Title XIX itself: namely, what are the fundamental federal policies that undergird this important source of federal domestic assistance? Following this discussion, the relationship of these basic policies to employing the Medicaid program to meet the needs of persons with developmental disabilities is discussed. Next, the evolution of federal Medicaid policies affecting developmental disabilities services is examined.

A. The Medicaid Program¹

The federal Medicaid program was enacted by Congress as part of the Social Security Amendments of 1965 (P.L.89-47), which also was the statutory basis of the Medicare program. Conceived less as a national health care strategy than as an attempt to "graft...a health program into a still voluntary system of state welfare assistance," Title XIX of the Social Security Act consolidated a predecessor program of federal participation in state payments for health care services furnished on behalf of AFDC recipients, as well as disabled and elderly persons. This earlier program, called the Kerr-Mills program, had emerged as an appendage to federally-assisted state welfare programs (Stevens and Stevens, 1974).

Since its inception, the Medicaid program has been conceived of as a means of providing federal financial participation in the costs of health care and related services selected by each state to be provided to public assistance recipients and -- at the option of the state -- other medically needy individuals. As a condition of federal financial participation in a state's medical assistance program, Title XIX law requires that states cover certain groups of public assistance recipients and agree to furnish a "mandatory" set of services to such individuals. Federal Medicaid law, fundamentally, is predicated upon granting each state wide latitude in defining the specific range and scope of Medicaid-reimbursable services and who will receive them. In particular:

A state has the authority to determine the income standards that regulate eligibility for public assistance benefits and, consequently, the threshold of eligibility for the Medicaid program.

A state may select from a myriad of "optional" coverages to supplement the mandatory services (e.g., inpatient hospital services) that it must furnish to eligible individuals.

A recent publication by the Congressional Research Service — Medicaid Source Book: Background Data and Analysis (1988) will furnish the interested reader with a far more detailed description of the Medicaid program.

In addition, a state is free to elect to cover any of a number of "optional" eligible groups of recipients that are established under Title XIX law.

A state may adopt limitations on the provision of services and, furthermore, may vary such limitations among groups of eligible recipients.

Finally, states have enormous flexibility in deciding levels of reimbursement for particular Medicaid services.

A state describes the range and scope of services it has decided to furnish in its state Medicaid plan, which - under federal law — must be administered by one agency, usually referred to as the "single state agency." With limited exceptions, once a state incorporates a service into its state plan, it must guarantee that the particular service will be available to all eligible individuals meeting the special conditions of eligibility it has incorporated within its state plan (and, hence, the characterization of the program as an "entitlement"). The "entitlement" nature of the program is viewed warily by states because it is difficult to control program spending once a service has been entitled.

At the federal level, the Medicaid program is administered by the Health Care Financing Administration (HCFA), an organizational unit of the Department of Health and Human Services (HHS). HCFA also is responsible for administering the Medicare program. Together the two programs involve over \$115 billion in federal outlays annually, making HCFA the third largest federal agency in terms of budget, exceeded only by the Department of Defense and the Social Security Administration.

The Medicaid program is considered an "entitlement" program in another important respect: namely, the federal government will participate on an unlimited basis in reimbursing a percentage of state service expenditures incurred in accordance with its approved state plan. Hence, Medicaid is an "open-ended" source of federal funding to the states in their efforts to furnish medical assistance to low-income individuals. Federal expenditures are driven by state choices concerning coverages and eligibility. The scope of a state Medicaid program, on the other hand, is tied to its capacity to supply its share (matching funds) of program costs.

Under the Gramm-Rudman-Hollings budget deficit reduction mechanism, federal Medicaid spending is exempt from "automatic" budget reductions in the event that federal spending exceeds the deficit reduction targets that have been established by Congress. To alter the level of federal Medicaid spending, Congress must enact specific changes in Title XIX statute designed to reduce program spending. Barring such changes, unlimited federal payments are available to support allowable service costs.

The essential character of the Medicaid program ~ namely, states exercising choices regarding service coverages and recipient eligibility under a broad federal umbrella of mandatory optional coverages and a plethora of service options — has been in place since the inception of the program. As a consequence, it is nearly impossible to describe the Medicaid program in a unitary fashion. The range and scope of the Medicaid program varies enormously from state-to-state. Each state has adopted its own benefit package and parameters for determining recipient eligibility. For example, in FY 1986, seven states accounted for over 50 percent of all federal Medicaid payments and over half of all Title XIX beneficiaries. (Congressional Research Service, 1988)

Congressional action to amend Title XIX of the Social Security Act typically involves potential expansions in the options available to states in the areas of service coverage or recipient eligibility. In recent years, however, national debate concerning federal Medicaid policies has focused increasingly on the degree to which coverage of certain services or recipient groups can be left to the discretion of states. For example, Congress has mandated that states cover certain recipient groups (principally, "pregnant women" and low-income children). In addition, a good deal of the national debate concerning "long-term care" reform on behalf of elderly persons centers on whether key services should be

federalized in order to provide for a basic, nationwide "floor" of coverage, irrespective of where a person may happen to reside.

B. Medicaid Policies and Developmental Disabilities Services

It is important to recognize that, in part, the debate concerning reformulation of Medicaid policies as they affect services to persons with developmental disabilities is in reality a debate concerning the premises of the Medicaid program itself. Namely:

To what degree should states be permitted to regulate the availability of certain services provided on behalf of persons with developmental disabilities?

To what degree should federal policies permit states to regulate eligibility for such services?

And, more specifically, to what degree should persons with severe disabilities be entitled to receive a "core" set of services?

At present, the specialized developmental disabilities services that a state may select to cover under its state plan are considered to be "optional services", and a state may limit such services at its own discretion.

Reflective of the general nature of the Medicaid program itself, states are given (and have exercised) a considerable degree of discretion in structuring eligibility for the optional state plan services they choose to furnish to persons with developmental disabilities. The plethora of possible choices available to a state, coupled with the linkages between Medicaid eligibility and a crazy-quilt of state, federal, and state/federal public assistance programs, is a source of much confusion regarding the nature of the Medicaid program.

The relationships between general Medicaid policies and Medicaid-reimbursable services furnished to persons with developmental disabilities may be examined in the context of three general aspects of Title XIX services: (a) eligibility, (b) types of services; and, (c) other related considerations.

1, Medicaid Eligibility

Under present Medicaid law, a state may tailor its eligibility criteria governing Medicaid-reimbursable long-term services to meet a variety of objectives. For example, a state may opt to narrow the disability test (by restricting the provision of services to persons with mental retardation) or specify relatively stringent criteria for determining an applicant's "need for institutionalization" (by delineating strict "level of care" criteria). With regard to the income and resources tests, a state must deem public assistance (SSI and AFDC) recipients to be eligible for Medicaid services but also may extend coverage to other optional groups that are recognized under Title XIX statutes. In the case of long-term care services, a state typically establishes a special income test (for example, the selection of the so-called "300 percent" rule). Such a special income eligibility test must apply to all recipients of Medicaid-reimbursable institutional services and may not be targeted solely to persons with developmental disabilities. A state, however, may establish a more stringent income test applicable to its HCB waiver programs. In summary, current Medicaid law grants states numerous choices concerning the type of persons who are treated as eligible to receive Medicaid-reimbursable long term care services, as long as a state's policies comport with basic federal, statutory provisions.

A fundamental principle of the Medicaid program is that a state must furnish the services it elects to cover under its state Medicaid plan to all eligible persons who need them. The major exception to this principle is that a state may restrict the provision of HCB waiver services to a limited number of individuals (i.e., the number of recipients approved by HCFA). States, however, typically control

"Related conditions" have been defined by HCFA to include cerebral palsy, epilepsy, or another condition (excluding mental illness) "found closely related to mental retardation" which results in substantial functional limitations in three of six enumerated "major life activities" (e.g., self-care; expressive/receptive language; learning; mobility; self-direction; and capacity for independent living).

The federal Medicaid definition of "related conditions" roughly parallels the definition of developmental disabilities in the federal Developmental Disabilities Assistance and Bill of Rights Act, although it specifically excludes mental illness and references certain etiological categories that were dropped from the federal developmental disabilities definition in 1978.

Presently, states have the authority to narrow the federal regulatory definition. Many states have done so in order to conform eligibility for specialized Medicaid services to state statutory eligibility laws. For example, a number of states limit the age of onset of the individual's disability to age 18 rather than 22 as provided under the federal definition. In other cases, states only serve persons with mental retardation.

Tied to the area of financial eligibility is the treatment of an applicant's/recipient's earnings. A key test of SSI-eligibility (and, consequently, Medicaid eligibility) is that a person's disability must prevent that individual from being gainfully employed. Until recently, SSI eligibility disqualified most persons with developmental disabilities who were capable of earning more than \$300 a month on a sustained basis from Medicaid benefits. In order to encourage the economic self-sufficiency of persons with severe disabilities, however, in 1986 Congress amended Titles XVI and XIX of the Social Security Act to extend SSI and Medicaid eligibility to certain persons whose earnings otherwise would make them ineligible for such benefits (Section 1619(a) and (b) of the Social Security Act).

Because states have such wide latitude in establishing Medicaid financial eligibility criteria, the Medicaid eligibility of persons with developmental disabilities varies considerably from state to state. While the SSI-eligible population is generally entitled to Medicaid benefits in all jurisdictions, states vary markedly in the extent to which children living at home are treated as Medicaid eligible, as well as individuals with severe disabilities who are ineligible for SSI benefits. With respect to the latter group, the principal population affected by individual state choices are persons with severe disabilities who receive a monthly OASDI (Social Security) check that disqualifies them (on the basis of financial need) for SSI benefits. In some states, such persons may be effectively locked out of the Medicaid program while in others they are covered.

The reader also should note that the scope of Medicaid coverage in a state is closely linked to a state's policies governing the supplementation of SSI benefits. States with more liberal supplementation levels generally have broader Medicaid coverage than those which have more restrictive supplementation programs. Again, state practice in this area is highly variable.

Types of Services Offered

The types of Medicaid-reimbursable services that are typically employed by states to meet the specialized service needs of persons with developmental disabilities are all categorized as "optional state plan" services or are linked to such state plan options in one fashion or another. This means that a state may choose to offer such services at its own discretion to eligible individuals. It also means that a state may impose limits on the "duration, frequency, and scope" of these covered services as it sees fit, so long as such limitations are equally applicable to all eligible persons. As with the area of Medicaid eligibility, the myriad of choices available to a state in designating certain Medicaid benefits to be furnished to persons with developmental disabilities is a root cause of the complexity in assessing present policies.

Only three statutorily designed Title XIX service categories may be deemed by a state to be exclusively available to Medicaid eligible individuals with developmental disabilities. The principle service in this category is the ICF/MR program (as authorized under Section 1905(d) of the Social Security Act). As an off-shoot of the ICF/MR program, a state may apply to the Secretary of HHS for a "waiver" in order to target home and community-based services to persons who otherwise would be admitted to an ICF/MR (as authorized under Section 1915(c) of the Social Security Act). Finally, a state may opt to furnish "targeted case management" services solely to persons with developmental disabilities (as authorized under Section 1915(g) of the Act). In the case of the last two options, the associated statutory authorities are "generic" in nature but a state, in order to furnish the authorized services, must designate specific target populations. These three options represent "specialized Medicaid-reimbursable developmental disabilities services."

In deciding to offer such services, a state has considerable latitude in how it might choose to do so as long as the services furnished comport with federal law and regulations. For example, ICF/MR services may be limited to persons who meet a specific "resident profile." Targeted case management services can be structured to include some, but not all, Medicaid-eligible persons with developmental disabilities and a state may further define the activities that will be performed on behalf of such persons. In the HCB waiver program, a state has relatively wide latitude in selecting the services it believes will best avoid institutionalization of a person. Further, a state can limit the frequency or costs of services.

Other categories of statutorily authorized Medicaid services also are employed by states in meeting the specialized needs of persons with developmental disabilities. These categories are distinguishable from the services described above because they cannot be specifically targeted solely to meet the needs of persons with developmental disabilities. These so-called "generic" services that some states employ as part of their overall service delivery strategy include "personal care", the "clinic option," and "medical rehabilitative services." Personal care services, which are intended to provide on-site assistance to an individual in areas of health-care maintenance and "activities of daily living" (and, as a subordinate aspect of service delivery, the provision of "chore" services) are employed by some states as part of multi-source financing strategies for residential support services provided in non-ICF/MR certified facilities. The "clinic option" and "medical rehabilitation services" are used (again, by some states) as a means to finance the costs of furnishing specialized daytime habilitation services to persons with developmental disabilities and usually encompass therapeutic, health maintenance, or "daily living" services.

Finally, some distinctly health-related services that a state may cover in its Medicaid state plan can be employed to address specific needs of eligible individuals with developmental disabilities. These include therapy services, home health, benefits available under the EPSDT program, and others. Services available in these categories are even less targetable than the preceding set of services.

From a service delivery standpoint, then, the interface between a state's developmental disabilities service delivery network and the state's Medicaid program involves choices concerning the state's utilization of specialized Medicaid-reimbursable developmental disabilities services, whether a state will use a limited number of other state plan services in a focused way to support daytime or residential services, and the extent to which broadly available Medicaid benefits may be accessed to meet specific needs. Since a state may limit each of these services (or opt not to provide some or all of them), a complex set of interrelationships typically arises ~ on a state-by-state basis — between developmental disabilities service delivery and the Medicaid program.

The fact that relatively few Medicaid services can be specifically targeted to persons with developmental disabilities means that the use of Title XIX financing often

becomes ensnared in a state's overall strategy for managing the Medicaid program. Attempting, for instance, to access personal care services on behalf of persons with developmental disabilities may trigger major issues vis-a-vis a state's strategy for managing long-term care services on behalf of the elderly.

3. Other Related Areas

To complete this portrait of the potential interactions between developmental disabilities service delivery systems and each state's Medicaid program, it is useful to point out several other features of present general Medicaid policies that have relevancy in this area:

First, present Title XIX law gives the states enormous flexibility in establishing rate determination methodologies applicable to Medicaid reimbursable services. As a consequence, states vary enormously in how they set payment rates and the level of payment rates. At the same time, however, current federal Medicaid policies and practices establish a framework for payments to providers of reimbursable services that are relatively rigid (often more rigid than those utilized by states in managing payments for state-funded services) (Smith, 1987).

Second, present law does not envision a direct administrative role for a state's mental retardation or developmental disabilities authority in the management of Medicaid-reimbursable services furnished on behalf of persons with developmental disabilities. A state, however, may contractually delegate some of the responsibilities of the single-state Medicaid agency to such an authority.

Third, embedded in the Medicaid program are a welter of administrative requirements that define in one way or another the tasks a state must accomplish in order to gain Medicaid reimbursement for services. For example, federal regulations establish relatively specific requirements concerning the types of contracts that may be entered into with a vendor of Medicaid-reimbursable services.

As in other aspects of general Medicaid policies, it is fair to say that present statutory and regulatory requirements at once sanction a state's exercising considerable discretion over management of the program while at the same time forcing a state that is interested in employing Medicaid-financing on behalf of persons with developmental disabilities to conform its policies and practices to Title XIX requirements that are themselves eccentric to the program.

In summary, it is fair to say that Medicaid-financing of developmental disabilities services leads to a considerable entanglement with an enormously complex program that presents an often-times confusing welter of options and eccentric requirements. As will become more evident in successive sections of this report, many issues associated with reformulating present Medicaid policies as they affect persons with developmental disabilities are themselves complicated by this entanglement.

C. The Evolving Role of Medicaid in MR/DD Services

Medicaid policies as they affect services to persons with developmental disabilities have been evolving for over twenty years. Present federal statutes and administrative policies represent the outcome of actions taken by Congress and federal administering agencies to interrelate the general framework of the Medicaid program to the specific service needs of persons with developmental disabilities. Today's Medicaid policy issues have their origins in such actions. Important lessons can be learned by examining the evolution of current policies.

1. The Advent of the ICF/MR Program

Although a limited number of states had employed Title XIX funding to finance state-run institutional services subsequent to the enactment of the Medicaid program in 1965, the direct involvement of the Medicaid program in developmental disabilities services began in late 1971 when Congress authorized, as an optional state plan coverage, services in intermediate care facilities for the mentally retarded (ICF/MR) (through the enactment of Section 1905(d) of the Social Security Act). At the time, this legislation was viewed as an expedient solution to problems that certain states were facing in financing institutional services for persons with mental retardation. In giving states the option of covering ICF/MR services, P.L. 92-223 attempted to create a special niche in Medicaid's long-term care services sector for state-operated mental retardation institutions that could not easily or appropriately be classified as generic nursing care facilities.

It is important to recognize that the legislation creating the option to cover ICF/MR services was not the product of careful legislative analysis and debate concerning the best methods of organizing and delivering long-term care services to persons with developmental disabilities. Indeed, no Congressional hearings were held on the proposal before it was enacted; furthermore, floor debate on this particular aspect of the 1971 legislation was minimal.

Rather, the ICF/MR statutory benefit was the result of the convergence of two key factors: (a) the states' interest in obtaining federal financial participation in the rising costs of operating state mental retardation institutions; and, (b) the desire of consumer groups (most notably the Association of Retarded Citizens) to upgrade the quality of services furnished in such facilities, by linking the receipt of federal funding to a facility's compliance with minimum federal standards. ARC's objectives were met by specifying in Section 1905(d) that a facility ~ in order to qualify for certification as an ICF/MR and, hence, qualify for state/federal Medicaid payments — would have to meet nursing facility safety and sanitation standards and also furnish "active treatment" services to its residents. The use of the phrase "active treatment" represented an attempt (however ambiguous and ill-defined) to assure that residents of ICF/MRs received "health and rehabilitative" services, rather than **merely custodial care.**

While few believed in 1971 that the ICF/MR state plan option necessarily represented the best or only means of assisting states to meet the needs of persons with developmental disabilities, it must be kept in mind that seventeen years ago, the most prominent feature of specialized mental retardation services in most states was large, state-operated institutions. Indeed, only four years previous state institutional populations had peaked at roughly 230,000 individuals (including nearly 35,000 individuals who resided in state mental hospitals) (Lakin et al., 1985).

-, Lacking a means of financing reasonably adequate services in these settings, other changes in federal Medicaid policies could have led to the disruption of services on behalf of literally tens of thousands of individuals who resided in public institutions. As a consequence, Section 1905(d) — Medicaid's only specialized service benefit available for persons with developmental disabilities ~ was intended to promote improvements in existing, institutionally-based services.

In 1974, the Department of Health, Education, and Welfare's Medical Services Administration (the predecessor agency to the present day Health Care Financing Administration) issued final regulatory standards that a facility serving individuals with "mental retardation and other related conditions" would be required to meet in order to be certified as an ICF/MR and, consequently, be eligible for Medicaid

See Lakin et al. (1985) for a more extended discussion of the various factors that combined to result in the passage of P.L. 92-223.

payments. These standards borrowed heavily from standards which had been promulgated by the Accreditation Council for Facilities for the Mentally Retarded (the predecessor to the present-day Accreditation Council on Services for People with Developmental Disabilities (ACDD)). Until they were finally revised in June 1988, these regulatory standards would define the framework for the provision of ICF/MR services for the next fourteen years.

The 1974 standards described a certifiable facility as one which furnished a comprehensive program of habilitative, maintenance, and health care services to each of its residents. Persons deemed appropriate for these services were described as individuals who needed "continuous" active treatment services. Primary responsibility for assuring the well-being of persons served in an ICF/MR was assigned to the facility (rather than an external entity), which was required to assess the needs of each resident across a variety of "life domains" as well as develop and implement an individual care plan for each resident. The regulations mandated the involvement of certain specialists (e.g., physical therapists and dietitians) in assessing each resident's needs and carrying out the individual care plan. Specific staffing ratios applicable to residential living units serving particular types of individuals — based on broad client characteristics — also were established. As a result, ICF/MR services were indelibly stamped as a highly intensive, "facility-based", "comprehensive care" mode of delivering services.

One critical outgrowth of the publication of the 1974 regulations was that the physical plant of an ICF/MR had to conform to nursing facility life safety code requirements, and living/sleeping areas had to afford residents a reasonable level of privacy. For example, resident bedrooms could accommodate no more than four residents and had to meet minimum square footage requirements set forth in federal regulations. Since residential living units in many state institutions were configured as open wards or large cottages, many facilities could not meet these new requirements, which were scheduled to take effect in March, 1977. Ultimately, after considerable debate, an accommodation was reached under which any state that was unable to comply with the applicable federal physical plant requirements was permitted to apply for a waiver of certain standards to gain additional time (but not beyond July, 1982) to bring its facilities into compliance while continuing to receive Medicaid payments. To qualify for a waiver that extended beyond July, 1980, however, a state had to agree to take steps to reduce the number of residents in each affected facility (Lakin et al., 1985).

The 1974 regulations and the subsequent step to offer states the option of delaying compliance had two critical consequences. First, the regulations triggered an enormous level of capital investment in state-operated mental retardation institutions in order to bring the physical plants of such facilities into compliance with federal regulations and, hence, guarantee the continued receipt of Medicaid payments. In fact, during a three year period, states expended over three quarters of a billion dollars to renovate existing state MR institutions, primarily to bring them into compliance with federal ICF/MR standards (Gettings and Mitchell, 1980). Second, numerous states put into motion "deinstitutionalization" plans, as a means of avoiding making expensive capital investments in antiquated or undesirable facilities. The extension of the federal compliance deadline through July, 1982 served as inducement to states to pursue such deinstitutionalization initiatives.

Thus, from late 1971 to the end of 1982, the implementation of the ICF/MR program dominated the states' Medicaid program agenda. There were several distinct outcomes of the states' efforts during this period:

First, the number of persons with developmental disabilities receiving Medicaid-assisted long-term care services rose rapidly. The number of persons occupying ICF/MR-certified beds jumped from 69,000 in 1975 to 106,000 in 1977 and again to 141,100 by

1982 (Lakin et al., 1985). As a consequence, federal Medicaid spending for these services literally exploded, increasing from roughly \$617 million in 1977 to approximately \$22 billion in 1982 (Braddock et al., 1986).

Second, the quality of care and the living environments of individuals residing in ICF/MRs improved substantially. Facility staffing levels were enhanced markedly; resident per capita expenditures rose at a pace well beyond the general rate of inflation.

- Third, the character of the population in state-run facilities began to change. As a result of "deinstitutionalization" efforts, which focused on placing less severely disabled individuals into community programs, state institutional residents increasingly could be characterized as multiply-handicapped.

Fourth, the enormous capital investments many states were required to commit in order to comply with the 1974 regulations resulted in a perception that the bed capacity remaining once compliance was achieved somehow represented a "permanent" state commitment to maintaining state-run institutional services.

Fifth, one result of the steps states took to reduce state facility population levels was an expansion in the number of privately-operated ICF/MR facilities, most of which tended to be relatively large by contemporary standards. In a number of instances, the states' efforts to reduce the populations of state-run facilities took the form of transferring individuals to "community-based" programs that were themselves "institutional" in character. Nonetheless, Medicaid funding for developmental disabilities services began to spread outside the walls of state-run institutions.

Sixth, a number of states seized upon special features of the 1974 ICF/MR rules to establish "small" (less than 16 bed) ICF/MRs as a means of infusing Medicaid financing into the private, community-based service delivery network.

Finally, the manner in which states collectively financed the costs of developmental disabilities services changed enormously. Medicaid came to represent a critical means of obtaining external financing for service enhancement and expansion. This particular change will be discussed in greater depth in the following chapter of this report.

There is no doubt that the initiation of the ICF/MR program has had far-reaching consequences for the delivery of services to persons with developmental disabilities. "Privatization" of service delivery emerged as a distinct trend. Incentives were created for states to "deinstitutionalize" residents to community-based programs. These incentives and other factors (e.g., judicial actions to protect persons with developmental disabilities, an increasing focus on establishing "community-based" services; etc.) combined to put into motion major changes in publicly-funded services to persons with developmental disabilities.

At the same time, however, it is important to recognize that, while the creation of the ICF/MR program had an major impact on publicly-funded service delivery systems through 1982, these effects were confined to what might be termed "conventional" service modalities. Federal policies were aimed at authorizing Title XIX reimbursement of residential, congregate care programs within the overall context of Medicaid funding for long-term care services. Federal policies were not

intended to establish a mechanism to assist states in purchasing a broad array of services on behalf of persons with developmental disabilities, regardless of the individual's living arrangement.

As a result, a two-tiered service delivery system emerged: Medicaid-funded congregate care services and state-funded community-based services, the latter principally supporting less highly structured residential programs and daytime services. With a few notable exceptions, the penetration of Medicaid financing into the mainstream of the states' community-based programs was relatively limited before 1982. While some states employed "generic" Medicaid coverages to assist in financing daytime habilitation services (under Medicaid's "clinic option" or the "medical rehabilitation services" category) and non-ICF/MR residential services (by employing Medicaid's personal care benefit), in most instances the underlying requirements associated with such coverages proved to be serious obstacles to the development of Medicaid financing strategies designed to increase the availability of Title XIX dollars in non-institutional community services.

In the evolution of community-based services then, Medicaid financing of congregate care residential programs served as an indirect catalyst to the reallocation of state expenditures from institutional to community-based services (a theme that will be discussed in greater depth in the following subsection of this chapter).

The period of the initiation and subsequent growth of the ICF/MR program had other important features that bear on the present debate concerning federal Medicaid policies. In particular:

Federal oversight of the ICF/MR program was not proactive during this period. While states and private provider agencies clearly were required to comply with the new regulations, direct, on-site federal oversight activities were virtually nonexistent. As a consequence, responsibility for regulating ICF/MRs devolved upon state survey agencies, which possessed little expertise in developmental disabilities services. In many states, this meant that ICF/MR surveys focused on areas of overlap between nursing facility and ICF/MR regulations (e.g., life safety code, dietary services, and medical services). As a result, "active treatment" remained a vague and largely unenforced concept.

States were able to exercise considerable discretion in determining eligibility for ICF/MR services. Some states adopted fairly restrictive tests, while others applied more open-ended criteria. Again, the vagueness of the concept of "active treatment" created an environment in which states had relatively wide latitude to determine the extent to which ICF/MR services would be employed as a device for financing specialized MR/DD services.

- The introduction of Medicaid into non-state operated facilities also brought with it other trappings of the Medicaid program that proved problematic in some states. Since Medicaid vendorizes payments and generally does not recognize the role of local substate agencies, some states found it difficult to integrate Medicaid financing of private ICF/MRs into their routine funding

Among the obstacles in employing these "generic" Medicaid benefits are: (a) the fact that they must be "prescribed" by a physician and generally supervised by trained medical personnel; and, (b) many states have found it difficult to target such services solely to persons with developmental disabilities.

systems for community services. In states where the state MR/DD agency and the single state Medicaid agency were located in separate departments, the use of Medicaid financing for community residences also proved to be a potential impediment to unified, strategic system planning. These factors tended to reinforce the evolution of a two-tiered system of delivering community services.

As an outgrowth of these and other factors, the authorization of the ICF/MR program had widely varying results, state-to-state. While, in general, most states seized upon the program as a means of financing state institutional services, the extent to which Medicaid financing was used to support community services and the overall impact it had on state service delivery systems varied markedly from one state to another. As will be discussed in the next chapter of the report, this high degree of variability persists today.

By 1982, the initial effects of the implementation of Section 1905(d) largely had been played out in most state-run institutions. However, the utilization of the ICF/MR program to finance an expansion of community-based services varied markedly from state to state. While some states (New York, Michigan, Minnesota, and others) regarded the ICF/MR program as a critical element in expanding community-based services, others viewed the program more warily. The largely non-interventionist posture of HCFA in overseeing this program led many state officials to conclude that the ICF/MR program represented a readily accessible means of employing Medicaid dollars to finance community-based services. Some states, however, were more aggressive in pursuing this financing strategy than others.

2. The Home and Community-Based Waiver Authority

In 1981, Congress enacted the "home and community-based" (HCB) waiver authority, by adding Section 1915(c) to the Social Security Act (Section 2176, P.L. 97-35). The enactment of the HCB waiver authority, like many other changes in Title XIX policy, was a product of many competing forces. Essentially, however, the objective of Section 1915(c) was to provide states with a means of employing Medicaid dollars to finance alternatives to placing elderly and disabled individuals in nursing facilities and other institutional settings (bettings, 1981a). Section 1915(c) was not the result of a conscious effort to change federal Medicaid policies as they affected persons with developmental disabilities; in fact, the themes stressed by Congress in its 1981 deliberations were very similar to the contemporary debate concerning how best to organize generic federal long-term care policies.

Under Section 1915(c), a state is authorized to propose to the Secretary of HHS a targeted program designed to furnish home and community-based services to individuals who otherwise would be institutionalized. Section 1915(c) requires a state to demonstrate to the Secretary's satisfaction that the proposed services are essential to prevent institutionalization and, furthermore, are "cost-effective" (i.e., the costs of providing such services would not exceed, on average, the costs of furnishing institutional services to eligible individuals). In addition, a state also is required to provide the Secretary with satisfactory assurances that the "health and safety" of individuals receiving HCB waiver services are adequately protected and that the right of an individual to select institutional services is not abridged, if he/she so chooses. The Secretary also is empowered to grant waivers of "statewideness" and "comparability" to a state requesting approval to furnish HCB services. These waivers permit states to target the availability of such services to particular recipient groups (e.g., elderly individuals), a practice not otherwise

possible under general Medicaid policies.

While the enactment of Section 1915(c) was not "developmental disabilities legislation," it resulted in a substantial change in how Medicaid dollars could be

employed on behalf of persons with developmental disabilities. Many states quickly recognized that the generic nature of the HCB waiver authority would permit them to design waiver programs that would serve as alternatives to expanding the number of ICF/MR beds. In essence, a second stream of Medicaid financing for developmental disabilities services had been created.

Moreover, states found that such programs could be designed in a manner consistent with their general approaches to delivering community-based services (Gettings, 1981a; Gettings, 1982). Beginning late in 1981 and continuing into 1984, a large number of states submitted waiver proposals and received HCFA approval to initiate home and community-based waiver programs targeted specifically to persons with developmental disabilities. These waiver requests, by and large, were aimed at qualifying community-based services for Medicaid financing that would not qualify as ICF/MR services. Typical services included in these waiver programs were: (a) case management; (b) residential support services in community group homes; (c) family care or supported living arrangements; (d) daytime services; and, (e) family supports (although to a relatively limited degree). As a result of this flurry of activity, by the end of 1984 Medicaid financing had been introduced into the "mainstream" of publicly-funded community-based services in a majority of the states.

This state activity to initiate HCB waiver programs was aided immensely by the apparent receptiveness of HCFA officials to the waiver requests submitted by the states. Proposed regulations implementing Section 1915(c) were issued in near record time. The first HCB waiver request (by Oregon) was approved by the Secretary in December 1981, barely two months after interim final regulations were issued. Federal officials, who had become increasingly alarmed by the rapid escalation in ICF/MR spending, viewed the HCB waiver program as a means of at least slowing the rate of growth in Medicaid spending for services furnished on behalf of persons with developmental disabilities.

The most notable ramifications of the enactment of the HCB waiver authority were the following:

Medicaid dollars could be directed to financing "supportive" service models, rather than being restricted solely to the "comprehensive care" ICF/MR model. Services could be "debundled" and provided on an intermittent basis. This financing mechanism, then, stood in sharp contrast to the ICF/MR program.

As a consequence, the flexibility afforded by the HCB waiver program was perceived by state administrators, providers, and advocates as a positive step toward permitting them to chart a more balanced approach to developing an array of Medicaid-financed MR/DD services.

States generally found that Medicaid HCB waiver financing could be integrated more readily into their existing methods of funding community-based services than was the case with the ICF/MR program. Assuring a consistent, systemwide approach to financing and delivering DD services was a key factor that led many states to implement waiver programs. In particular, "external case management services" could be employed as a means of coordinating the provision of services. This model of service coordination was more consistent with community service delivery systems in many states than the facility-based approach of the ICF/MR program.

States concluded that the HCB waiver program would permit them to exercise greater control over service standards and program

costs. A similar degree of state empowerment was not feasible under the ICF/MR program; federal standards ~ although not strongly enforced prior to 1984 — could not be unilaterally modified by states.

At the same time, however, Section 1915(c) demanded that eligibility for such services be tested against the "need for institutionalization." Home and community-based services were viewed as an alternative to institutional care services rather than as legitimate service modalities in their own right. Due to the absence of an operational federal definition of what constituted "need for institutionalization," this lack of independent standing for HCB waiver services, however, was viewed as being an eccentric rather than a problematic feature of Section 1915(c).

- In many states, the state MR/DD agency emerged as the administering agency for Medicaid-reimbursable DD long-term care services provided via the waiver program. While not mandated by the legislation, most states found it more convenient to work out administrative agreements which assigned responsibility for day-to-day management of waiver services to state MR/DD agencies rather than the single state Medicaid agency.
- Medicaid financing of community-based developmental disabilities services became more deeply-ingrained. The HCB waiver program (and, to a lesser degree, the ICF/MR program) provided a means by which many states could cope with the declining level of federal Social Services Block Grant funding (SSBG; see the "Title XX" program). Title XX had served as a key source of federal financing of community services, but since 1981 has declined in importance due to the cutbacks in federal domestic assistance that began in the late 1970s.

Thus, however unintended, the enactment of the HCB waiver authority represented a pivotal event in the evolution of federal Medicaid developmental disabilities policies. The identification of Medicaid financing with institutionally-based services, while not severed, was substantially altered. By the end of 1983, slightly more than half the states had submitted HCB waiver program applications to HCFA and gained approval.

Rising Tensions in Federal-State Relations

Beginning in 1983 and accelerating throughout 1984, important changes occurred in federal-state relations surrounding the provision of Medicaid-financed developmental disabilities services. In many respects, the ramifications of these changes are still being played out today. Thematically, the federal government's historically passive role in administering Medicaid-reimbursable developmental disabilities services gave way to a new era of: (a) proactive oversight of the ICF/MR program; and, (b) the introduction of federal Medicaid cost containment objectives into payments for developmental disabilities services. This assertion of a more proactive federal role stands in stark contrast to the "hands-off" attitude that had characterized federal-state relations over the previous decade.

a. The Look-Behind Initiative

Prompted by evidence of apparent, widespread deficiencies in ICF/MRs in a number of states, Congress instructed HCFA in 1984 to shed its "non-interventionist" regulatory posture and "look-behind" the quality of care surveys performed by state survey and certification agencies to determine

directly whether Medicaid-certified ICF/MRs were complying with federal standards (Katz and Gettings, 1986). While the Secretary of HHS had been granted the authority to perform such "look-behind" surveys in 1980 (by amendments to Section 1902(a)(33)(B) and Section 1910(c)(1) of the Social Security Act), HCFA had only rarely invoked this statutory authority.

Principally targeted on larger state-operated ICF/MRs, the "look-behind" surveys initiated by HCFA in late 1984 found significant deficiencies in a number of facilities, particularly in the provision of "active treatment" services. As a consequence, numerous facilities were either required to submit plans of correction and/or threatened with decertification (and, consequently, loss of federal funding). In addition, HCFA set up - again at Congressional direction - oversight capabilities in each of its regional offices in order to establish an ongoing program of federal ICF/MR look-behind surveys. HCFA also undertook specialized training of state survey agency personnel designed to assure that such staff understood and applied federal standards in their survey activities.

From a federal policy perspective, HCFA's "look-behind initiative" has had three critical ramifications:

- First, HCFA was forced to define more precisely the standards of compliance for Medicaid-certified ICF/MRs. While previously HCFA had supplemented the 1974 regulations with "interpretative guidelines" to assist surveyors in assessing facility compliance, those guidelines provided only general direction to state survey agencies. This was particularly true in the area of "active treatment." Soon after initiating its ICF/MR "look-behind" program in 1984, HCFA developed a survey protocol which, for the first time, established more specific guidelines defining what constituted "active treatment" and the essential processes that a facility needs to put in place in order to assure the delivery of mandated services.

Second, in enforcing ICF/MR standards, federal surveyors established performance expectations related to facility staffing and the utilization of clinicians/specialists that markedly increased the baseline level of "adequate" staffing that a facility needed in order to achieve compliance. It became clear that furnishing "active treatment" services meant maintaining richer staffing ratios than many states had previously believed were necessary. The "threshold of compliance" escalated rapidly.

Finally, the "look-behind" initiative changed Congressional views regarding the degree to which states could be entrusted with principal administrative responsibility for Medicaid state plan services furnished to persons with developmental disabilities. More federal policymakers came to believe an active, interventionist federal oversight was needed to protect persons with developmental disabilities.

The federal "look-behind initiative" altered perceptions of what constituted reasonable standards of ICF/MR services. Ultimately, these standards were codified in revised federal ICF/MR regulations which were issued by HCFA in June, 1988 (after being on the drawing board for nearly six years).

From the perspective of the states, the "look-behind initiative" has had critical ramifications. In particular:

- The "economics" of financing state-run institutions and employing privately-operated ICF/MRs as a component of community service delivery systems changed substantially. ICF/MR costs escalated rapidly in the wake of both federal and state compliance activities (a trend that will be discussed in Chapter HI).

As had occurred previously with state efforts to comply with the 1974 ICF/MR regulations, the "look-behind initiative" prompted many states to rekindle formal "deinstitutionalization" plans to reduce the populations of state-run facilities and, hence, contain the costs of maintaining ICF/MR compliance. Rather than employing privately-operated ICF/MRs as a means of reducing state institutional populations, however, the HCB waiver program emerged as an important vehicle for maintaining federal financing of services to these individuals. Again, federal regulatory activities had the effect of accelerating the historical rate of decline in state facility census levels.

Finally, state attitudes concerning the Medicaid program and federal oversight were deeply affected. State officials recognized that federal actions could threaten continued receipt of a critical source of revenue used to support the delivery of developmental disabilities services. As a result, many states began to reevaluate the wisdom of their increasing dependence on Medicaid financing.

The "look-behind initiative," then, must be viewed as a watershed in federal-state relations regarding Medicaid-reimbursable services for persons with developmental disabilities. A new, increasingly cautious (and, oft-times adversarial) relationship between the federal government and individual states emerged. The adoption of an interventionist regulatory stance by the federal government caught many states ill-prepared to deal with the assertion of more definitive guidelines concerning ICF/MR compliance.

b. Administrative Constraints on Federal Outlays

At approximately the same time the "look-behind initiative" was launched, the Reagan Administration set in motion a series of administrative steps designed to rein in federal Medicaid outlays for long-term care services to persons with developmental disabilities. While, on the one hand, states were experiencing a significant escalation in the costs of ICF/MR services (as an outgrowth of the "look-behind initiative") the Administration was seeking avenues to reduce Medicaid outlays or at least contain their rate of increase.

The Reagan Administration came into office with the explicit policy objective of reducing the role of the federal government in supporting domestic programs. With respect to the Medicaid program, early Reagan Administration proposals to achieve this objective took the form of proposals to "cap" federal Medicaid payments to the states and index future increases in such payments to variables not directly related to state expenditures. The Reagan Administration viewed containing federal outlays in the Medicaid program as a key element in its overall strategy for reducing total federal outlays, while at the same time reallocating current

dollars to support a build-up in defense spending (Gettings, 1981b; Gettings, 1981c).

While accepting some Reagan Administration proposals to reduce federal Medicaid outlays (e.g., in 1981 Congress voted to temporarily reduce federal Title XIX matching payments to states), Congress rejected the notion of "capping" the Medicaid program. Successive Administration proposals to cap the program also were rebuffed in each year through 1987 (principally due to the efforts of the Democratic majority in the House, spearheaded by Representative Henry Waxman (D-California)). In 1988, the Administration finally dropped this proposal as a result of the "budget summit" which set the parameters for the federal FY 1988 and FY 1989 budgets.

Failing to contain Medicaid spending by capping federal outlays, the Administration turned to examining the root causes of the rapid increase in Medicaid payments to states. What became immediately clear to the President's Office of Management and Budget (OMB) was that state claims for Medicaid-reimbursable ICF/MR services had skyrocketed and, in fact, were the principal driving force in the rapid escalation of Medicaid-reimbursable long-term care expenditures. Containing Medicaid long-term expenditures, then, became synonymous with restricting Title XIX's participation in the costs of developmental disabilities services.

Lacking Congressional support to change federal law to contain such expenditures, attention turned to administrative measures that might be used to accomplish the same objective. Two courses of action were adopted. In the area of ICF/MR services, the allowability of state claims for federal payments was brought under considerable scrutiny, particularly with respect to whether states were claiming reimbursement for "educational" and "vocational" expenditures which were not Medicaid-reimbursable. Special audits were undertaken by the HHS Office of the Inspector General; a number of states were threatened with substantial disallowances of federal Medicaid payments for having claimed federal funds for purported educational or vocational services (Gettings, 1985).

Simultaneously, OMB instructed HCFA to tighten up on its approval of HCB waiver requests. States encountered greater difficulty in obtaining approval for such requests. In addition, HCFA officials began to impose more stringent tests of "cost effectiveness" than had been used previously or were intended by Congress. (Gettings, 1985) For example, a state might be told by HCFA that its HCB waiver program would not be approved unless the average per capita cost of HCB services were no greater than 75 percent of institutional costs.

In 1985 and 1986, ultimately, Congress reacted to these efforts by adopting certain cost containment steps that were viewed as excessive and inappropriate. Congress, for example, declared a variety of modifications in the Social Security Act to prohibit the Administration moratorium on disallowances for educational and vocational services until HCFA clarified its policies in this area. In addition, Section 1915(c) was amended to prevent HCFA from imposing special tests of the "cost effectiveness" of proposed waiver services or disallowing state claims for reimbursement in the event that waiver spending exceeded the state's original estimates.

The objective of cutting federal Medicaid payments to states did not entirely die with the budget submit. President Reagan's last budget reportedly includes a proposal to reduce the federal Medicaid matching rate by 3 percent.

While Congress stepped in to protect the states (and to assure that the Administration did not impose a cap on Medicaid outlays administratively), the die nonetheless had been cast that states would face special administrative scrutiny in their utilization of Medicaid-reimbursable services on behalf of persons with developmental disabilities. The tenor of federal-state relations became more adversarial, a situation that persists to the present day. State experiences with HCFA during this period reinforced their caution regarding the Medicaid program as a means of financing services that meet the needs of persons with developmental disabilities.

In addition, while Congress demonstrated a willingness to countermand the Administration's attempts to employ administrative measures to contain Medicaid outlays on behalf of persons with developmental disabilities, it also implicitly sanctioned HCFA's more stringent regulation of the HCB waiver program. In particular, HCFA was successful in establishing that its approval of a state's HCB waiver program was contingent upon the state's agreeing to accept a cap on the total number of recipients of Medicaid-reimbursable DD long-term care services. Limiting waiver utilization as well as the number of ICF/MR beds became a primary condition of HCFA approval of an HCB waiver request. As a result, the waiver program could no longer be viewed as a reliable, long-term and elastic means of marshalling Medicaid dollars to respond to community services demand. Thus, while the HCB waiver program is allowed to play the role of assisting a state in reallocating Medicaid dollars from institutional to community-based settings, the HCB waiver program could not serve as a readily expandable source of federal assistance in responding to new community service demands. Indeed, an attempt by Senator Bill Bradley (D-New Jersey) and Representative Ron Wyden (D-Oregon) to convert the HCB waiver program to an optional state plan service - and thus free it of HCFA-imposed caseload limitations - received little support in the 99th Congress.

In summary, then, the events surrounding the federal look-behind initiative and the Administration's attempts to contain federal Medicaid outlays on behalf of persons with developmental disabilities marked the beginning of a new era in federal-state relations. The federal government would adopt a more proactive, interventionist role in the use of Medicaid dollars to support state service delivery systems. Developmental disabilities services were no longer immune from efforts to slow the pace of federal budgetary outlays.

Recent Events and Current Status

Since 1985, a relatively limited number of changes have occurred in federal Medicaid policies as they affect persons with developmental disabilities. In many respects, the past three years have seen a continuing reaction to the events that unfolded during 1982-1985. The "look-behind initiative," for example, appears to have become a permanent feature of ICF/MR regulation. States continue to encounter problems in obtaining HCFA approval for HCB waiver programs (either for new requests or periodic renewal applications for current programs). Federal audits are continuing and are having serious ramifications in some states. In many respects, a very uneasy air has settled over federal-state relations.

Congressional action has taken place, however, that indicates that federal policies in this field are gradually evolving, albeit at a slow, incremental pace. In particular

In 1986, Congress authorized the limited provision of "prevocational" and "supported employment" services to HCB waiver recipients. This change represented a marked departure

from previous Title XIX policy, which prohibited the use of Medicaid funding for "vocational" services.

Also, in 1986, Congress authorized a new, optional state plan service, entitled "targeted case management services." Again, while this service was not intended exclusively for persons with developmental disabilities, it has obvious, potential ramifications for community-based MR/DD services, which rely on the provision of case management as a key coordinative activity in furnishing supports to persons with developmental disabilities.

In the Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203), Congress reaffirmed a step it had taken in 1986 (in conjunction with the passage of P.L. 99-457) to assure that spending for "related services" delivered to special education students was considered an allowable Title XIX expenditure when furnished to Medicaid recipients.

Finally, also in OBRA-87, Congress established new restrictions on serving persons with developmental disabilities in "generic" nursing facilities. While the full impact of this change in policy is unclear, at least 40,000 individuals nationwide will be affected by this change in policy. One clear ramification of this "nursing home reform" legislation is that the utilization of both ICF/MR and HCB waiver services will be dramatically affected in most states. Under the legislation, some nursing facility residents with developmental disabilities must be transferred to more appropriate settings. Other residents must be furnished "active treatment" services. The blocking of new nursing facility admissions also will place additional pressure on already strained community service delivery systems in many states (Gettings et al., 1988).

Finally, Congressional deliberations concerning "nursing home reform" also revealed that some key members of Congress believed it imperative that federal oversight of ICF/MR and Medicaid-reimbursable community services should be further strengthened. While no specific statutory changes were adopted by the 100th Congress, it seemed clear that some Congressional leaders were in a mood to expand federal regulation of community-based MR/DD services financed with Medicaid dollars.

Hence, while Congress has not dealt with what many observers believe to be several of the key issues regarding Medicaid policies affecting persons with developmental disabilities, it continues to take incremental steps that collectively have significant implications.

D. Conclusion

Federal Medicaid policies affecting services to persons with developmental disabilities have undergone substantial changes over the past twenty years. In many respects, some of these changes are still being played out: either in the form of state reactions to federal initiatives or in further refinements of directions established by Congress a number of years ago.

Federal policies have not evolved in any consistent, unified manner. Present policies never have been undergirded by a clear, distinct set of federal policy goals and objectives. In part, this is a reflection of the basic nature of the Medicaid program itself: i.e., the organizing premise of the program remains to create an umbrella of allowable services under which individual states may define their own particular responses to the needs of low-income individuals. Given the ambiguity of federal policy objectives, it is not surprising that the

present debate surrounding the reformulation of these policies centers on imposing more well-defined objectives governing Medicaid-reimbursable MR/DD services.

Medicaid's involvement with developmental disabilities services began with finding a place within the Title XIX program for large, state-operated institutions. The legacy of that decision is one source of the current frustration with the Medicaid program: in one way or another, this "institutional bias" in Medicaid-reimbursable services is viewed by many as a substantial obstacle to further expanding community-based services.

The enactment of the HCB waiver program — far more than efforts by a limited number of states to adapt "generic" Medicaid benefits to financing community MR/DD services — stands as a pivotal event in creating an alternative perspective on using Medicaid funds on behalf of persons with developmental disabilities. Medicaid funding no longer necessarily had to be synonymous with the provision of residential services in congregate care settings; federal Medicaid dollars also could be employed to finance "supportive" services. Administrative limitations imposed by HCFA on state HCB waiver programs (with the tacit approval of Congress), however, clearly point to the fact that the HCB waiver program can serve only a transitional step toward defining a reliable, broad-based means of employing Medicaid dollars in community developmental disabilities programs.

Next, the "look-behind" experience has highlighted many critical issues in this policy arena. First, the ICF/MR program is increasingly becoming isolated from mainstream service delivery, since it has become a highly costly and tightly regulated means of furnishing specialized long-term care services to persons with developmental disabilities. Second, it seems clear that federal involvement in financing MR/DD services will bring with it federal oversight of the quality of services that are furnished to eligible recipients. The "non-interventionist" era appears to have drawn to a close.

Finally, it seems evident that Medicaid-reimbursable DD long-term care services cannot avoid being drawn into the debate concerning federal spending. Congress thus far has been unwilling to liberalize the HCB waiver program to permit states to expand the use of Medicaid financing for community-based services. While Congress has demonstrated that it will resist Executive Branch attempts to reduce Medicaid-reimbursable services, it has been loath to entertain all but relatively incremental changes in present policies when such changes might have significant fiscal impact.

The historical evolution of Medicaid policies as they affect services to persons with developmental disabilities provides key insights into current policy issues as well as potential directions for future change. In the next chapter of this report, the evolution of these policies will be examined from the standpoint of their fiscal and service utilization impacts on state MR/DD service delivery systems.

CHAPTER III

MEDICAID'S ROLE IN FINANCING DEVELOPMENTAL DISABILITIES SERVICES: THE DEEPENING ENTANGLEMENT

III. MEDICAID'S ROLE IN FINANCING DEVELOPMENTAL DISABILITIES SERVICES: THE DEEPENING ENTANGLEMENT

The critical need for basic reforms in federal Title XIX policies affecting services to persons with developmental disabilities comes into sharper focus when the role Medicaid dollars have played in the evolution of state service delivery systems is examined. Within the larger context of the reconfiguration of publicly-financed MR/DD services (i.e., from institutionally-dominated to community-centered systems), Medicaid financing of services has played a key role. At the same time, however, any objective examination of the present distribution of Medicaid dollars across service delivery sectors reveals a fundamental malalignment of resources. Indeed, serious questions can and should be raised about whether present policies are contributing to or inhibiting the achievement of key nationwide policy objectives.

The objective of this section of the report is to provide the reader with information regarding Medicaid's past and present role in financing services to persons with developmental disabilities. A variety of existing data is synthesized in an attempt to assist the reader in understanding the pervasive influence Medicaid has on present state/local decisionmaking and, consequently, the enormous potential impacts of changing current federal policies. In one way or another, reformulating current policies will affect approximately \$6 billion in federal/state spending. The unresolved issues surrounding the federal budget deficit inevitably require that proposals for Medicaid reform be scrutinized in terms of their potential effects on federal domestic spending. Hence, understanding the scope of current spending is as just as essential an ingredient in the current debate concerning Medicaid reform as are ideological objectives and philosophic values.

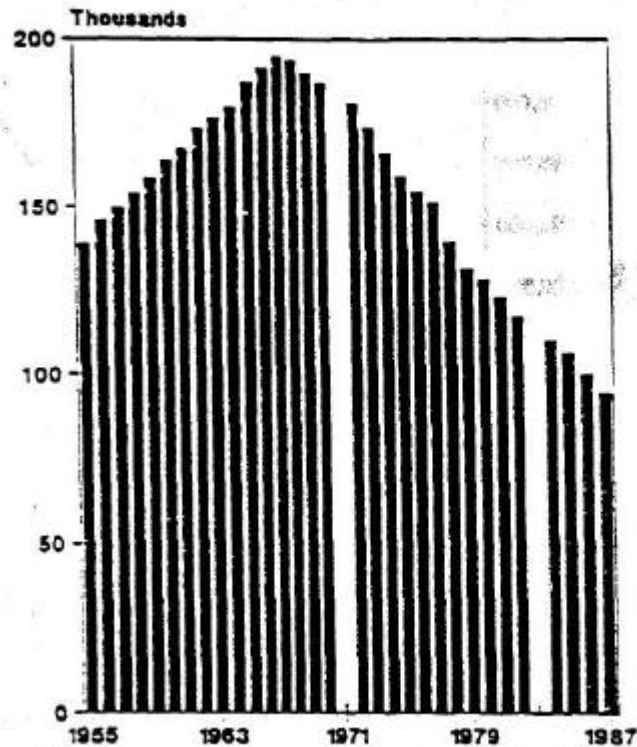
In this chapter, key trends in the delivery of state services to persons with developmental disabilities are discussed to establish the context within which the debate concerning the reformulation of Medicaid policies is taking place. Attention then will be turned to an examination of the growing use of Medicaid dollars to finance specialized developmental disabilities services and the ramifications of this trend. Finally, the emergence of new (and, heretofore, largely unrecognized) issues in Medicaid-financed services will be highlighted in order to pinpoint the growing nationwide concerns with current Title XIX policy directions.

A. Transformation in Service Delivery Systems

Twenty years ago, the concept of publicly-financed developmental disabilities service delivery was largely synonymous with institutional services provided in large, impersonal, and often poorly staffed and maintained facilities operated by the states. Segregation and custodial care represented the most likely fate of individuals who could not be cared for by their families. Although in the 1960s community-based MR/DD service systems were beginning to emerge in many states, the fact remained that persons with severe disabilities faced a bleak future if public-funded services were required.

In the short span of twenty-years, however, there has been a fundamental realignment of service delivery systems in most states. The chart at the top of the following page shows the steady, continuing decline in the number of individuals served in state-operated residential facilities. As can be seen from this chart, the number of persons served in state-run facilities peaked in 1967 at approximately 195,000 persons (224,000 if persons residing in state mental hospitals are included) (White, et al., 1987). By 1977, the number of persons in state-run facilities had fallen to approximately 152,000, or a reduction of slightly more than 20 percent. By 1986, approximately 100,000 persons were served in such facilities, a reduction of about one-third in ten years (White et al., 1987). By the end of 1987, the number of persons

**Average Daily Population of Public
Residential Facilities for Persons with
Mental Retardation and Developmental Disabilities:
1955-1987 (fig. 1)**



Source: Congressional Research Service, 1988

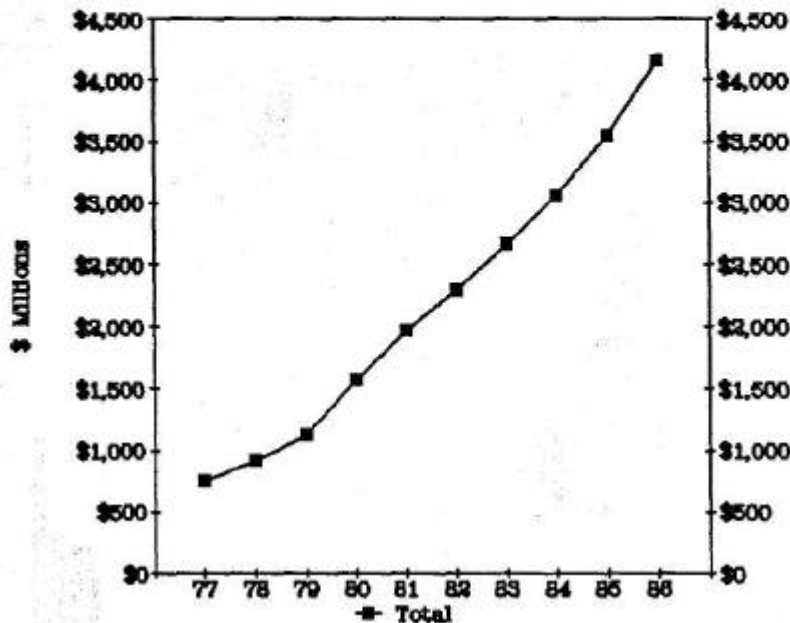
residing in public mental retardation facilities had fallen to approximately 93,000 individuals or less than half of the level of twenty years earlier (Scheerenberger, 1988).

There were (and continue to be) a wide variety of reasons for this steady, continuing decline in the role of the state-operated MR/DD facility as the hub of state service delivery systems. Litigation, ideology, economics, initiation of new federal policies (e.g., the "Education for All Handicapped Children's Act of 1975"; Pi. 94-142), changes in Medicaid policies, and a myriad of other factors. It is literally impossible to isolate one factor or another as the singular or most decisive cause. While the pace of institutional reductions has differed in each state, this trend clearly is observable nationwide.

At present, there is no reason to expect that the trend toward fewer residents in state-operated residential facilities will not continue at approximately the same pace for the foreseeable future. Many states have active efforts under way to continue to downsize or close state-operated facilities that will directly affect institutional population levels over the next four-five years (Scheerenberger, 1988). Furthermore, many of the factors that have contributed to the ongoing decline in institutional populations continue to influence state decision-making as it impacts the utilization of such facilities.

Roughly paralleling the decline in the role of state-operated institutions has been the development and expansion in nearly every state of community service delivery networks dominated by private sector agencies. The chart at the top of the following page shows just how rapidly public spending on community MR/DD services increased between 1977 and 1986. In constant dollar terms, spending for community services tripled over this ten year period. As will be discussed below, Medicaid financing played an important, albeit catalytic, role in this rapid growth in public spending for community services. Efforts by states to

**Community MR/DD Services
Spending: 1977-1986
(fig. 2)**



Source: Braddock et al., 1986

place institutional residents in community facilities/programs also were a major factor in the growth of the private service delivery sector. Other key contributing factors included growing public confidence in community-based services as well as a willingness on the part of many states to significantly expand spending for human services programs during the 1970s.

By 1986, spending for publicly-operated and privately-operated services had approximately reached parity (Braddock, 1986). It is safe to predict that today a majority of state and federal dollars are supporting privately-operated, community-based services. While many are quick to point out that a significant share of these resources are tied to congregate care settings — rather than "true" community supportive services — and also that a disproportionate share of Medicaid dollars continue to be "locked up" in state-run institutions, the fact remains that the hub of developmental disabilities service delivery in the United States has been shifted from the institution to the community. For example, of the 250,000 individuals with developmental disabilities receiving residential services nationwide, over 60 percent are served by private agencies in community residences; ten years ago, only 40 percent were (Lakin, et al., 1988). Today, state MR/DD service delivery systems serve roughly 500,000 individuals and less than 20 percent reside in state-operated facilities.

As a consequence of these enormous shifts over the past twenty years, state MR/DD service delivery systems — in the aggregate — have been decentralized and privatized. The role of the state institution as the hub of service delivery has been displaced by community service networks that provide a diverse array of services.

There seems little doubt that this transformation will continue, given the steady decline in institutional populations. In addition, the range and scope of community services are changing. While nationwide data is sorely lacking in this area, community services during the 1980s have been characterized by a period of ferment in many states. In particular:

Community residences are becoming smaller; in many states, a "six-bed" standard is common for community-residential facilities. In the past, ten to fifteen-bed facilities were considered by some as innovative.

The small group home, as the principal means of delivering community-based residential services, is now being challenged by "supported living arrangement" programs, designed to furnish varying levels of assistance to persons with developmental disabilities in a wide-variety of living arrangements that utilize non-specialized housing and typically place no more than one-two individuals at a single site.

More and more states have initiated and expanded "family support service" programs, designed to bring respite care and other services to assist families in maintaining their son or daughter at home.

In daytime services, the hegemony of "day and work activity centers" and the "sheltered workshop" has been challenged by the rapid development of supported employment programs that attempt to secure and sustain integrated employment opportunities for persons with developmental disabilities (Katz and Gettings, 1987).

Increasingly, community-based programs are responding to the unique needs and special challenges posed by persons with low incidence conditions (e.g., autism and other severe behavioral disorders).

Finally, community MR/DD service systems have matured sufficiently to recognize the need to diversify, in order to ensure that there are a variety of appropriate service responses available to meet the needs of persons with developmental disabilities at various stages in their lives.

Hence, the very concept of "community services" itself is being redefined. In some respects, publicly-funded community services in the 1970s assumed the "comprehensive care" model that was pioneered in institutional settings. In the 1980s, community-based services continued to expand but began to establish their own identity. Arguably, community services in the 1990s increasingly will be "supportive" in nature (i.e., furnishing targeted interventions and assistance to persons in the community, while stressing the themes of integration and normalization).

While the course towards continued reconfiguration and transformation of state-managed and funded developmental disabilities services appears to have been charted, difficult problems lie ahead. In particular:

Most state MR/DD service delivery systems are confronted with extensive and growing waiting lists for services, as states struggle to keep up with the demand posed by the increasing numbers of special education graduates who need continuing services and supports.

With state government surpluses at a twelve-year low, state MR/DD programs are encountering growing difficulty in securing real increases in resources to support community-based services.

Finally, the rapid rate of growth in community-based MR/DD services in many states has created a complex backlog of financing, administrative, and quality assurance problems that must be addressed. The range and scope of community services grew rapidly, growth, however, did not necessarily result in the creation of a sound service delivery infrastructure.

The promises and problems of developmental disabilities services in the United States form the backdrop against which the debate concerning Medicaid reform will occur. It seems clear that the traditional framework within which this debate has occurred -

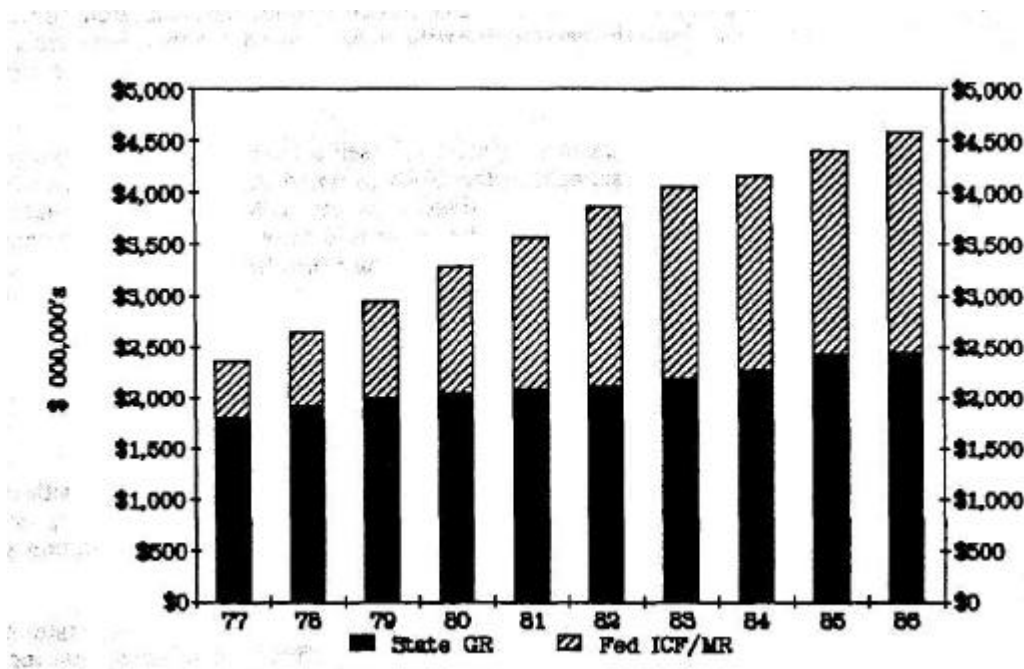
institutional versus community services — has been superseded by the events of the past twenty years. Today, the more critical issues are how can federal policies be changed in order to better reflect the current structure of service delivery and reinforce, rather than impede, emerging trends in the provision of services.

B. Medicaid Financing: Its Expanding Role In State Service Delivery Systems

As numerous commentators have pointed out, since the mid-1970s, Medicaid has become the dominant federal source of funding for institutional and community-based services to persons with developmental disabilities. Access to open-ended federal dollars via Medicaid's ICF/MR program was the most critical factor in expanding Medicaid's role in financing services to persons residing in state institutions and facilitating the development of community services. In almost all states, the increase in Medicaid dollars that resulted from the certification of state institutions as ICF/MRs provided a ready means of shifting a portion of the costs of these facilities to the federal government and, thus, freeing up state dollars to support a major expansion in community-based services.

The chart below depicts the amounts of state general revenue spending and federal ICF/MR payments in state-run facilities between 1977 and 1986.:

**Financing of State MR/DD
Institutions: FY 1977 - FY 1986
(fig. 3)**



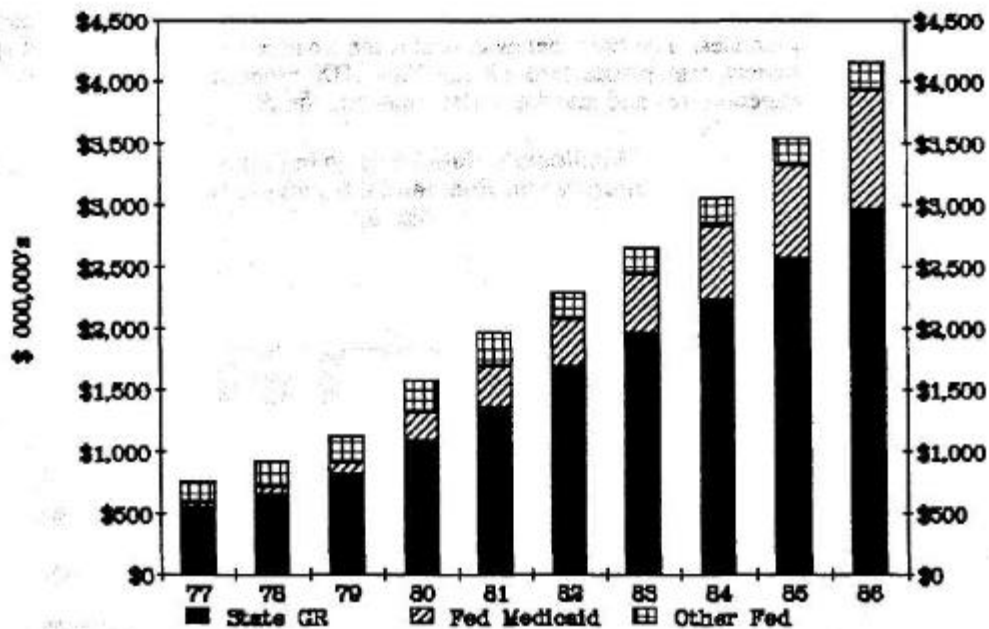
Source: Braddock, et al., 1986

As illustrated by the chart, total spending on state-run institutional services increased by 92 percent over this ten-year period. In real dollar terms (e.g., discounting the effects of inflation), however, such spending increased by only about 5 percent. More significantly, state general revenue expenditures, increased by only 36 percent while federal ICF/MR payments increased by 275 percent.

As a result of these increased federal payments for state institutional services, approximately \$990 million in state institutional spending was shifted to the federal ICF/MR program. Over this same period, state general revenue spending on community-based services rose by 570 percent. The ability of states to contain state general revenue expenditures for institutional services by shifting costs to the federal ICF/MR program was a critical factor in making possible the rapid increase in state spending for community services. Roughly 42 percent of the growth in state general revenue spending for community-based services can be traced to this shift in financing institutional services.

This phenomenon is further illustrated by examining trends in the financing of community MR/DD services. The chart below shows the sources of state and federal funding of community services between FY 1977 and FY 1986:

**Financing of Community MR/DD
Services: FY 1977 - FY 1986
(fig. 4)**



Source: Braddock, et al., 1986

While Medicaid funding of community services grew rapidly during this period, it did not result in any diminution in the relative level of state support for such programs. Both state and federal funding of community services remained relatively constant as a share of total expenditures for such services throughout this period. Medicaid dollars displaced Title XX (the other principal source of federal assistance for community services) as a means of employing federal dollars in community programs, while state funding of such programs continued to hold constant at about 70 percent of total expenditures. Until the advent of the Medicaid home and community-based (HCB) waiver program, Medicaid's role in

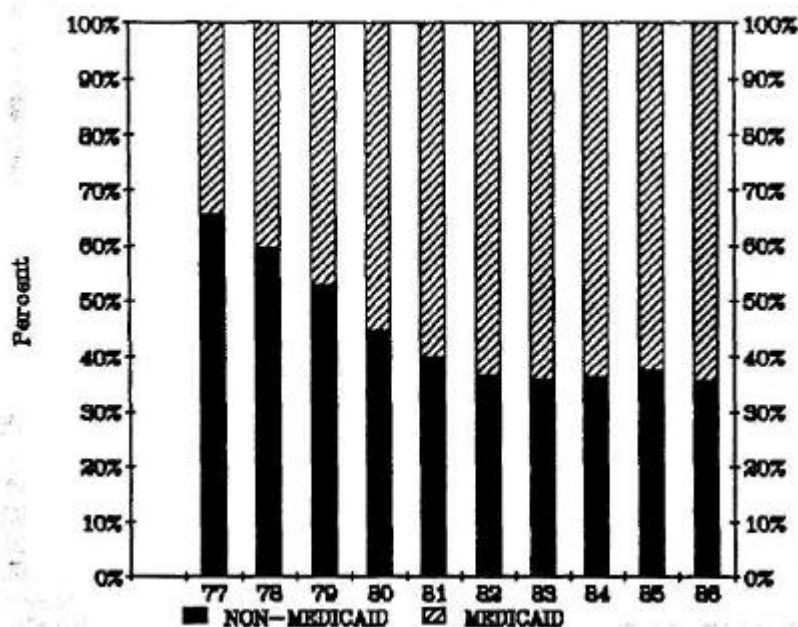
This shift is calculated by determining the share of FY 1986 expenditures that would have been financed from state general revenue sources had the state share of institutional expenditures remained at FY 1977 levels.

financing developmental disabilities community services was limited primarily to supporting larger privately operated ICF/MR facilities and, in a limited number of states, supporting daytime services through "generic" Title XIX plan options. [N.B., a few states ~ most notably Michigan and New York - also employed Medicaid's "personal care" benefit as a means of financing a portion of the costs of community residences.] Even as late as 1986, 75 percent of the individuals who resided in privately-operated ICF/MRs were served in facilities serving 16 or more individuals (Lakin et al., 1987).

While direct Medicaid financing of community services generally has played a less decisive role in most states than the reduced reliance on the state general revenue dollars in state facilities, federal Title XIX had a significant impact on the organization and delivery of community services. When federal Medicaid funds are combined with associated state matching dollars, the total share of aggregate community spending financed through the Medicaid program has risen substantially. In 1977, only 10 percent of all state/federal expenditures for community services occurred as part of the Medicaid program; by 1986, 42 percent of all such spending was channelled through the Medicaid program (Braddock, et al., 1986). Shifting from Title XX funding (due to the cap on federal grants) to Medicaid financing of community services did not raise the relative level of federal support for community MR/DD services; however, it did result in a growing share of community program spending falling under federal Medicaid requirements.

In general, Medicaid financing has come to dominate public funding of developmental disabilities services. The chart below indicates the trend in the relative share of spending for MR/DD services that passes through the Title XIX program, by adding together federal Medicaid expenditures and mandated state matching funds:

**Medicaid's Relative Role in Financing
Community and Residential Services: 1977 - 1986**
(fig. 5)



Source: Braddock et al., 1986

In 1977, about one third of total state spending was tied to the Medicaid program. By 1986, state/federal Medicaid payments accounted for approximately 65 percent of all program expenditures. In other words, nationwide about \$2 in every \$3 dollars spent by states on

behalf of persons with developmental disabilities now is linked, in one fashion or another, to federal Medicaid policies.

While this expansion in the use of Medicaid dollars frequently has clashed with other state objectives (e.g., promoting more integrated housing opportunities and vocational services for persons with developmental disabilities), the benefits derived from the influx of additional federal assistance, on balance, helped to offset the costs associated with upgrading institutional facilities to meet federal ICF/MR standards. In most states, the need to access new resources to expand the scope and range of services available to persons with developmental disabilities outweighed concerns about the facility-based bias of the Medicaid program. The ready availability of Medicaid dollars permitted states to refinance and upgrade institutional services with federal funds and, consequently, reallocate state dollars to community-based services. In addition, Medicaid provided a means of maintaining the federal share of the costs of community programs in the face of a freeze on federal Title XX funding.

Despite the unquestionable benefits of increasing utilization of Medicaid to finance developmental disabilities services, the price most states have paid is the introduction of federal policies as a major service delivery factor. Changes in federal Medicaid policies, thus, can have enormous potential impacts. The linkage between federal Medicaid payments and required state matching funds means that federal requirements leverage a disproportionate share of overall state spending relative to the actual federal Medicaid dollars a state receives. States have taken advantage of this leveraging effect to garner additional federal support: the simple truth, however, is that such leveraging also works in reverse by magnifying the ramifications of federal policy changes.

C. Critical Trends in the Use of Medicaid Dollars

The preceding discussion of the "macroeconomics" of Medicaid support for developmental disabilities services reveals a great deal about how such dollars have affected the organization and delivery of MR/DD services in most states. Nonetheless, there are particular facets and trends in Medicaid financing of developmental disabilities services which also bear examination. In part, it is useful to understand the present topology of Medicaid support for such services. A clear group of key trends also represents an important step toward understanding the possible ramifications of existing policies.

1. Who Receives Medicaid Supported Services?

By one reckoning, there are 1,200,000 Americans with mental retardation or other related conditions who, given the nature and extent of their disabilities, can be expected to need supportive services over their entire lifetime. (ASPE/HHS, 1988) Generally, these individuals are currently eligible for federal Supplemental Security Income (SSI) payments (747,000 individuals, including 596,000 adults and 151,000 children) and/or Social Security (OASDI) disability benefits (an additional 316,000 individuals). Such eligibility, in turn, is based on an assessment that a person's level of disability is likely to prevent him/her from engaging in employment. Additional adjustments in this data yield the estimated total of 1.2 million Americans (800,000 adults and 400,000 children) with developmental disabilities who have substantial handicapping conditions and "are likely to need long-term support." In addition, 450,000 of these individuals (270,000 adults and 180,000 children) are believed to be severely to profoundly disabled (ASPE, 1988). While these estimates may understate the number of persons who might benefit from publicly-funded developmental disabilities services (e.g., "prevalence" measures suggest a total U.S. population of persons with mental retardation of 2.4 million and broader definitions of developmental disabilities would raise the total even further), they represent a reasonable basis for estimating the total number of persons most likely to need MR/DD training and support services.

In 1987, approximately 172,000 individuals resided in ICF/MRs or received HCB waiver services. Estimates suggest that another 40,500 individuals with

developmental disabilities resided in Medicaid-certified nursing facilities (Lakin, et al., 1988). In addition, an unknown number of individuals receive Medicaid-financed daytime services in approximately eight states, plus an unknown number of individuals receive Medicaid-financed case management services in about a dozen states. [N.B., a rough estimate is that case management coverage may extend to as many as 40,000 individuals once these states fully implement their coverage plans.]

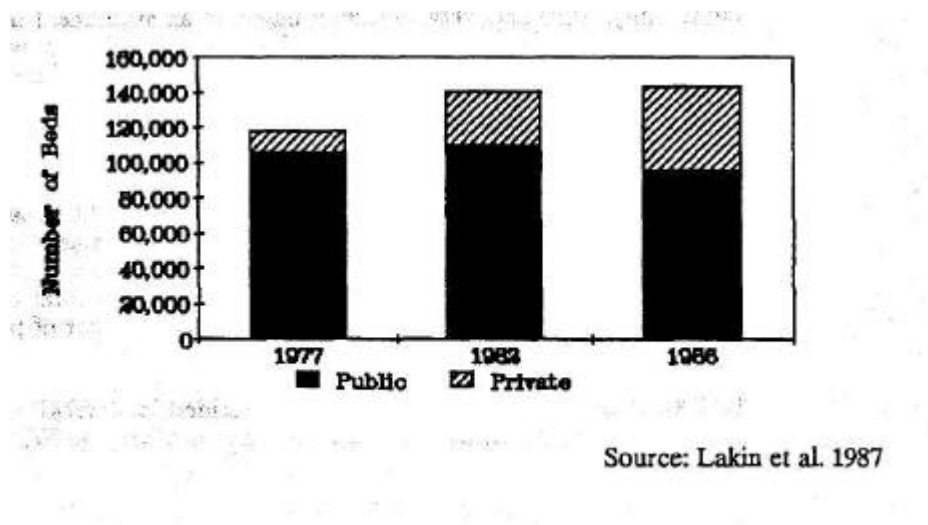
While the available data is not fully reliable (especially with regard to services other than those furnished in ICF/MR and HCB waiver programs), it is clear that "mainstream" programs, such as HCB waiver and ICF/MR services cover only about 15 percent of the potentially eligible population. In addition, the oft-stated criticism of present Medicaid policies — namely that they have resulted in a malalignment of resources ~ appears to have basis in fact. As pointed out earlier, state-federal Medicaid spending represents approximately 65 percent of total public spending for specialized MR/DD services, nationwide; yet, these dollars are currently supporting only about 35 percent of the persons who receive publicly supported MR/DD residential and daytime services.

Thus, despite the apparent rapid rate of growth in state/federal Medicaid outlays on behalf of persons with developmental disabilities, the fact remains that these dollars support only a relatively small number of Americans who are eligible for SSI or OASDI benefits and, based on prima facie evidence, are likely to need some combination of extended supportive services.

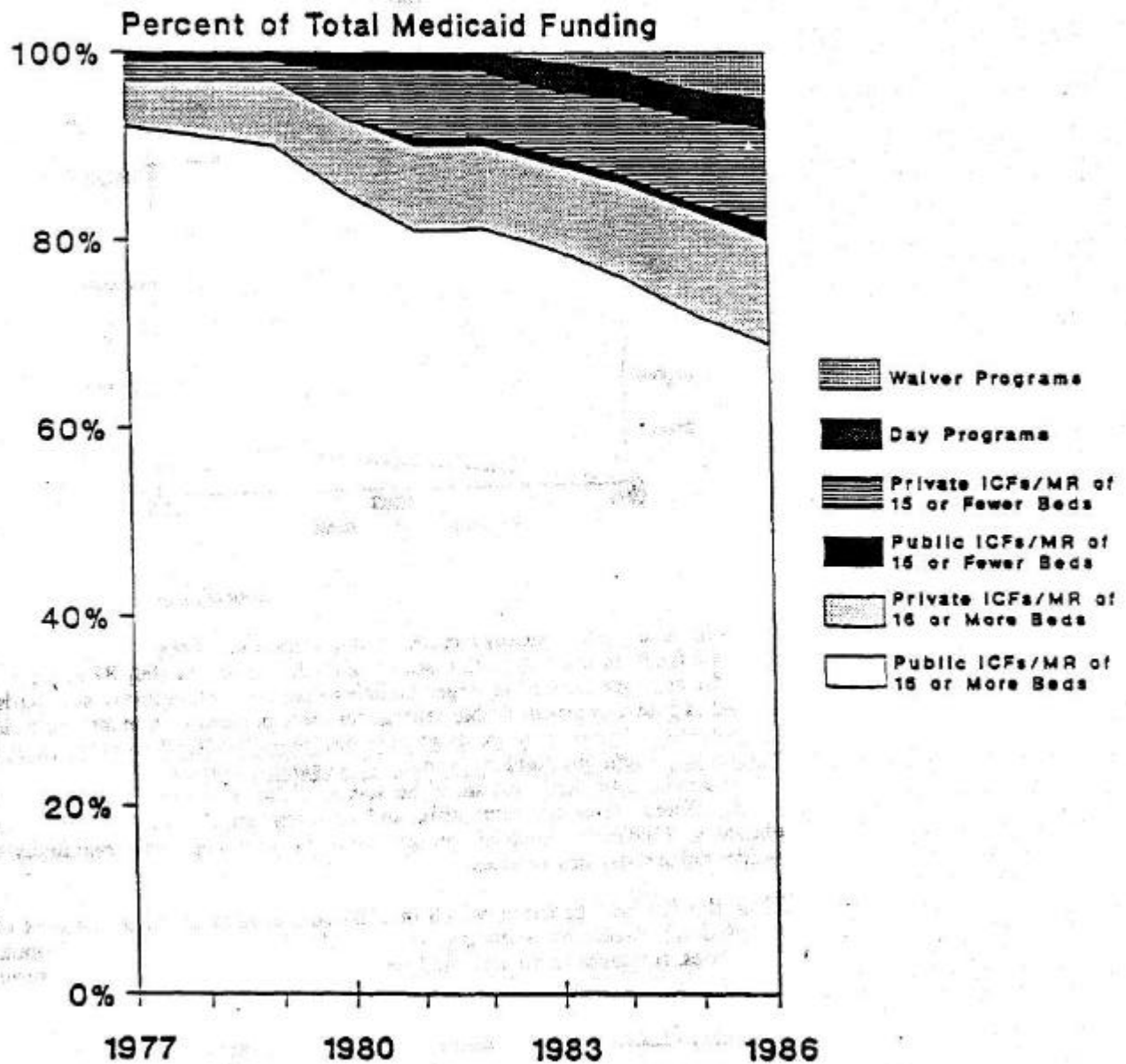
How are Medicaid Dollars Used?

The now familiar criticism of current Medicaid policies is that they have resulted in an inordinate amount of state/federal funds flowing into larger institutional settings. The chart (fig. 6) on the following page displays the distribution of state-federal Medicaid spending on behalf of persons with developmental disabilities from 1977 to 1986. Obviously, this chart indicates that the bulk of federal Medicaid dollars, historically, has been committed, and continues to be committed, to support services furnished in larger congregate care settings, either publicly or privately-operated. At the same time, it also is clear that smaller ICF/MR residences (15 beds or less) and the home and community-based waiver services have made some inroads into the institutional dominance of Medicaid spending in recent years. Within the ICF/MR program, there has been a pronounced trend toward the delivery of services through private vendor agencies, particularly since 1982, as illustrated by the next chart (fig. 7).

**Public-Private ICF/MR Beds:
1977-1986 (fig.7)**



**Allocation of Medicaid
Funding for Persons
with Developmental Disabilities:
1977-1986
(fig. 6)**

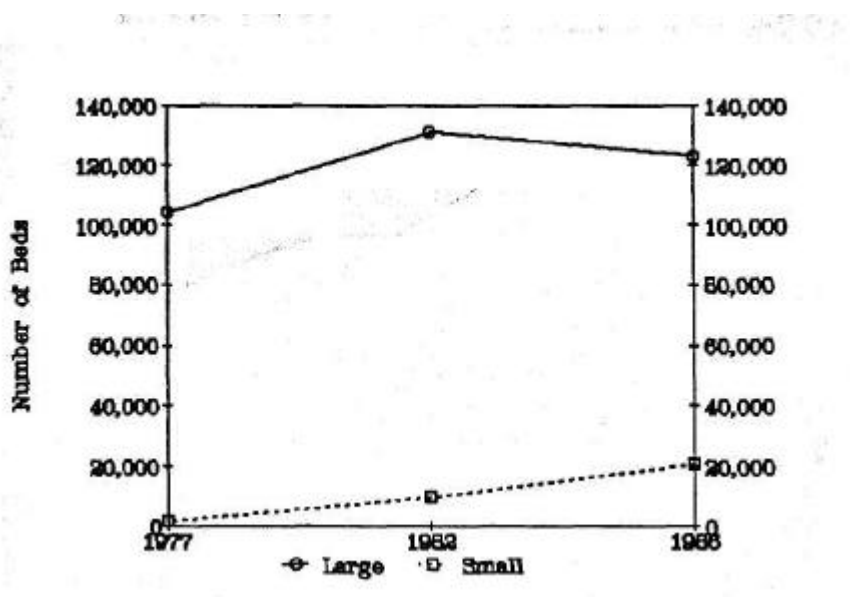


Source: Congressional Research Service, 1988

The number of recipients in state-run ICF/MR facilities peaked in 1982 and has been declining ever since. While the ICF/MR program continues to be primarily identified with state-operated institutions, the role of such facilities is receding, while private sector involvement is increasing.

Next, it is important to recognize that the ICF/MR program continues to be identified with the provision of congregate residential services in relatively large (greater than fifteen bed) facilities. The chart below shows the change in the distribution of ICF/MR beds located in large and small facilities since 1977:

**Large v. Small ICF/MR Beds
1977-1986**



Source: Lakin et al., 1987

While there has been a steady increase in the proportion of residents served in small ICF/MR facilities since 1977, the fact remains that approximately 87 percent of all ICF/MR beds are located in larger facilities that, by contemporary standards, are viewed as generally less desirable settings for most persons with mental retardation. For a variety of reasons, most states have not found the ICF/MR program to be a particularly useful mechanism for developing smaller community residences. This conclusion is particularly true since the advent of the HCB waiver program in 1981, which offered states an alternative, and in many ways more flexible means of obtaining Medicaid financial participation in the cost of community-based residential and daytime services.

Thus, the ICF/MR program, which in 1986 commanded about 95 percent of all state/federal Medicaid spending on behalf of persons with developmental disabilities, continues to be identified with congregate residential services furnished primarily in large public and private residential facilities.

How Uniformly Available Are Medicaid Financed Services?

The extent to which states have employed Medicaid dollars to support developmental disabilities services varies significantly from state to state. In 1986, for example, nationwide there were 60 certified ICF/MR beds per 100,000 U.S. population. In nine states, however, the number of ICF/MR beds per 100,000 population exceeded the national "norm" by 50 percent or more; in contrast, seven

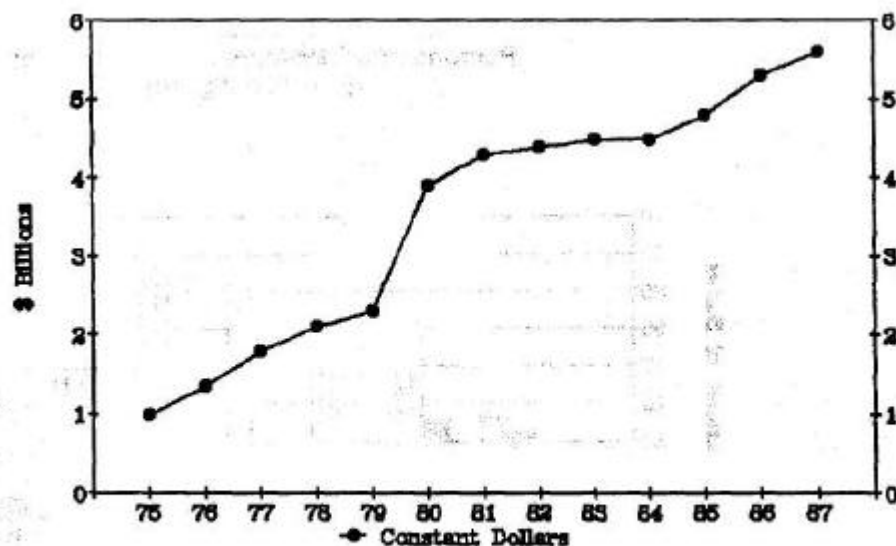
states utilized the ICF/MR program at less than one-half the nationwide average (Lakin et al., 1987). Hence, the ICF/MR program has had differing impacts among the states; these differential rates of Medicaid utilization also are reflected in the HCB waiver program. Furthermore, states vary considerably in the relative role Medicaid financing plays in meeting the needs of persons with developmental disabilities. In three states, for example, about 90 percent of all residential beds (both institutional and community-based; public and private) are Medicaid-certified ICF/MRs; thirteen states, however, had 40 percent or less of all beds certified as ICF/MRs (Lakin et al., 1987).

As a consequence of this variability, it is difficult to attribute to the Medicaid program any clear-cut, nationwide role in supporting developmental disabilities services. Consequently, in any effort to reformulate existing Medicaid law, it is important to keep in mind that access to Medicaid-financed services is highly uneven from state-to-state and, thus, modifications in such policies will have differing effects in each state. This high degree of variability among the states in the use of their Medicaid program leads to significant difficulties in forging nationwide strategies designed to alter the flow of federal Medicaid funds on behalf of persons with developmental disabilities.

How Rapidly Are Federal Expenditures Growing?

Over the past few years, Congress and the Reagan Administration have struggled (with only limited success) to reduce the federal budget deficit. The Gramm-Rudman-Hollings deficit reduction targets have become more difficult to achieve with each passing year. In the face of these efforts, however, state/federal Medicaid expenditures for developmental disabilities services have continued to grow at a pace far in excess of the general inflation rate - a trend that has been observed since at least 1975. The chart below displays Medicaid MR/DD expenditures expressed in constant dollars (i.e., factoring out the effects of inflation):

**State/Federal Medicaid Spending on
Behalf of Persons with Developmental Disabilities:
1975-1987 (fig. 9)**



Source: Burwell, 1987

While the rate of spending increase slowed during the early 1980s, it has recently reaccelerated (a topic that will be explored in greater depth later in this chapter). In recent years, ICF/MR spending has been increasing at a rate of 9-11 percent annually. HCB waiver spending has increased at an even faster pace (see below). Currently, the Congressional Budget Office estimates that, under current law, state/federal spending for Medicaid-reimbursable MR/DD services is increasing at an overall rate of 11.5 percent (Congressional Budget Office, 1988).

As a consequence of this high rate of growth, increased spending for ICF/MR services accounted for 15 percent of all the growth in Medicaid outlays between 1975 and 1986. In 1975, the ICF/MR program only accounted for 3.1 percent of total Medicaid outlays; by 1986, the ICF/MR program accounted for 12.4 percent of total Title XIX outlays and represented the third largest component of the Medicaid program overall (spending for nursing facility and inpatient hospital services ranked one and two) (Congressional Research Service, 1988). At the same time, it is important to keep in mind that ICF/MR recipients only represent 0.6 percent of the estimated 23.3 million Medicaid beneficiaries nationwide (Congressional Research Service, 1988).

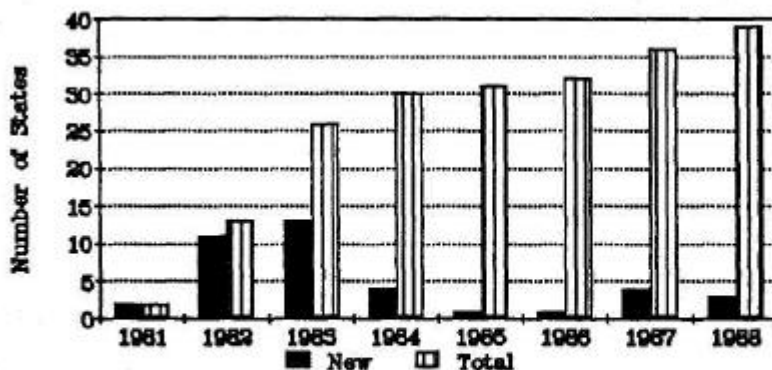
Hence, Medicaid outlays on behalf of persons with developmental disabilities thus far have escaped the fate of many other federal domestic assistance programs. The question can be raised — as it undoubtedly will for the entire Medicaid program ~ of whether this protection will continue to hold in the future.

What Effect Has the HCB Waiver Program Had?

In Chapter II of this report, the proposition was advanced that the HCB waiver program represents a potentially critical, transitional step in the reformulation of Medicaid policies as they affect persons with developmental disabilities. While HCB waiver spending only commands approximately five percent of Medicaid outlays for developmental disabilities long-term care services, it nonetheless has significantly altered public perceptions of how Medicaid dollars may be utilized.

Today, 39 states operate or are about to initiate HCB waiver programs specifically targeted to persons with developmental disabilities. The number of states with such HCB waiver programs has continued to increase, as evidenced by the following chart:

**States with HCB Waivers Serving
Persons with Developmental Disabilities:
1981 -1986 (fig. 10)**

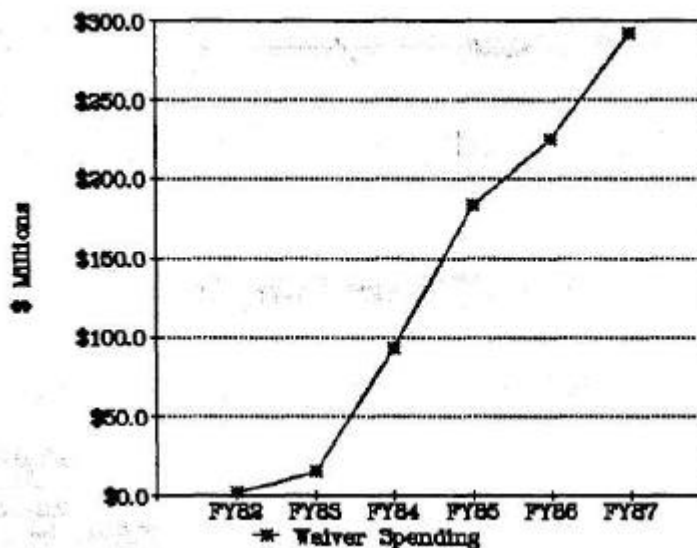


Source: HCFA

Following the enactment of the HCB waiver authority in 1981, states seized upon this new financing alternative; by the end of 1984, 60 percent of the states had HCB waiver programs in operation. Since 1984, the growth in the number of waiver programs has slowed. Still, over three-quarters of the states have now selected this option, despite the myriad of problems that have emerged in state-federal relations surrounding this program.

Again, despite the Reagan Administration's efforts to slow the rate of increase in HCB waiver expenditures, a very rapid rate of increase has been recorded since 1982, as evidenced by the following chart:

**HCB Waiver Expenditures
for MR/DD Services
1982-1987: (fig. 11)**



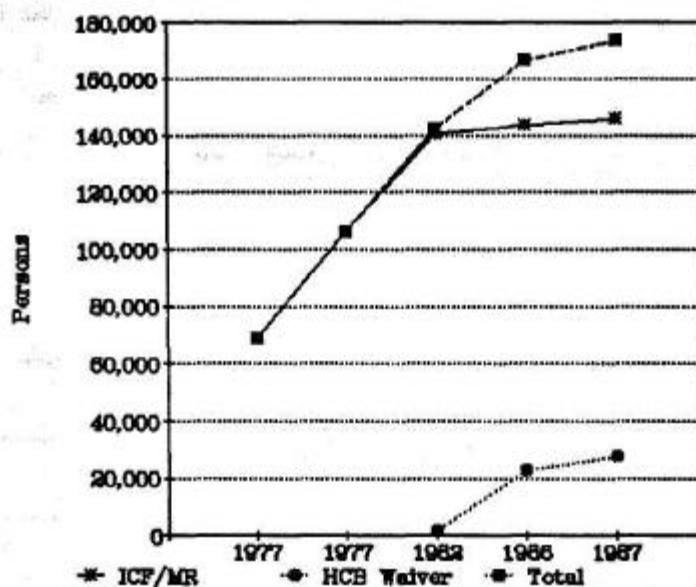
Source: Various

This rapid rate of growth in waiver expenditure is likely to continue for the foreseeable future as more states bring waiver programs on line or expand current programs, either under present HCFA authorizations or to further reduce institutional populations.

Finally, the impact of the HCB waiver program also may be gauged by its effects on the utilization of Medicaid-reimbursable long-term care services. The advent of the HCB waiver program has led to a major shift away from the ICF/MR program as a vehicle for furnishing Medicaid reimbursable long-term care services to persons with developmental disabilities. The results of this shift are dramatically illustrated by the chart at the top of the following page. Between 1975 and 1977, the number of persons residing in ICF/MRs grew by nearly fifty percent. Between 1977 and 1982, it grew again by about one-third (from 106,000 to nearly 141,000). Between 1982 and 1987, however, the growth in the number of ICF/MR residents slowed significantly. By the end of 1986, there were approximately 144,000 ICF/MR residents. In about half the states, the number of ICF/MR certified beds actually fell between 1982 and 1986 (Lakin et al., 1987).

In contrast, state HCB waiver programs, which only began to come on line in 1982, had grown to serve approximately 28,000 persons by 1987. In other words, since 1982 nearly all of the net growth in the number of persons receiving Medicaid-

**Developmentally Disabled Recipients
of Medicaid-Reimbursable
Long-Term Care Services
1975-1987 (fig. 12)**



Source: Various

reimbursable long-term care services has occurred as a result of the initiation and expansion of HCB waiver programs. The fact that three-quarters of the states have opted to furnish HCB waiver services and, consequently, agreed to limit ICF/MR utilization strongly argues that the number of ICF/MR beds nationwide, has peaked and may actually decline in the future. [N.B., the recently adopted provisions of OBRA-87 relating to nursing facility residents with developmental disabilities, however, may - for a variety of reasons - result in a near-term increase in the number of ICF/MR certified beds (Gettings et al., 1988).]

One important factor in this very rapid redirection of Medicaid financing on behalf of persons with developmental disabilities probably is that HCB waiver services have proven to be substantially more economical than ICF/MR services. In 1986, for example, the average per capita cost of waiver services were only about one-third of the \$35,139 annual per capita costs of ICF/MR services.

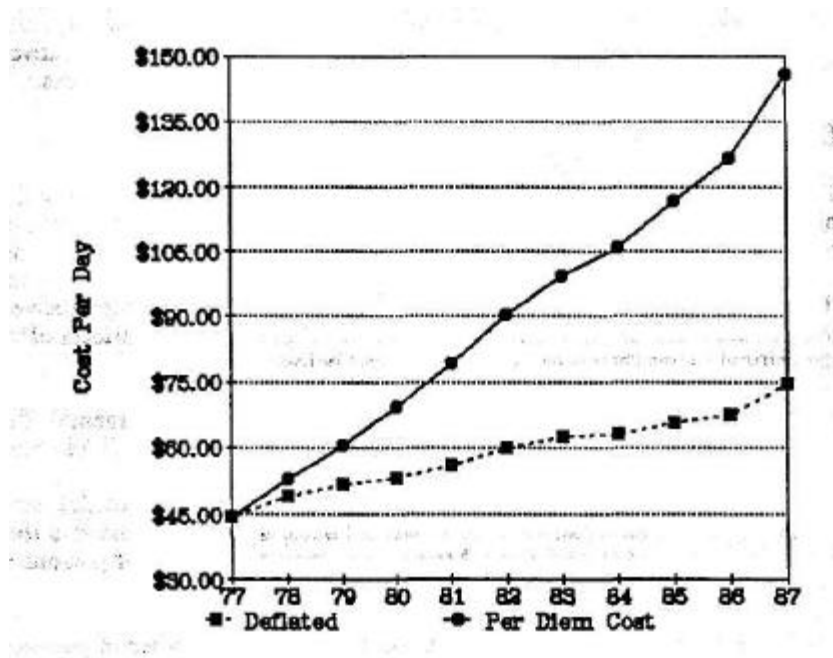
Despite the relatively minor fiscal impact of the HCB waiver program at present, then, experience with this program to date suggests that it contains the seeds of possible answers to some thorny questions surrounding the provision of services to persons with developmental disabilities - not the least of which is that those are ways of structuring less resource-intensive services than those provided through the ICF/MR program in order to place states in a better position to meet the burgeoning demands for services.

6. What Has Been the Impact of the Look-Behind Initiative?

Where once the ICF/MR program was a relatively trouble-free means of accessing federal dollars, it now represents a growing fiscal liability to the states. The rapidly escalating costs of ICF/MR services serves as a drain on state resources. The chart

below depicts state institutional per diem costs, in both actual and constant dollars, between FY 1977 and FY 1987:

**Public MR/DD Facilities
Per Diem Costs:
1977 -1987 (fig. 13)**



Source: Braddock, 1986; Scheerenberger 1987

Between FY 1981 and FY 1984, institutional per diem costs rose by approximately 13 percent in real dollar terms. By 1984, it appeared that institutional per diem costs were beginning to stabilize; the rapid increase during the preceding period reflected the states efforts to comply with the 1974ICF/MR regulations. But, in the latter part of FY 1984, HCFA initiated federal "look-behind" surveys to assess compliance with federal ICF/MR regulations. These surveys were focused initially on state-operated facilities. As a result of these surveys, a number of states were required to substantially intensify services in state institutions in order to maintain ICF/MR certification and, thus, continuation of Medicaid funding. Between FY 1984 and FY 1987, institutional per diem costs rose by 18 percent in real dollar terms. While it is impossible to attribute this 36 percent increase in the rate of growth in state institutional per diem costs solely to the states responses to federal "look behind" surveys, there is no doubt that increased federal scrutiny was a major factor. Based on available data in total state institutional spending, the largest absolute increase (\$299 million) since FY 1979, occurred between FY 1986 and FY 1987. During this year, state facility spending rose by approximately 8 percent despite an estimated 7 percent reduction in the number of individuals residing in state-operated facilities (Braddock, 1986; Scheerenberger, 1987).

While forecasts of future changes in institutional costs necessarily must be guarded, it seems likely that this rapid rate of increase in real per capita costs will continue; in many states, the fiscal effects of "look-behind" surveys have not as yet been fully reflected in national expenditure data. The recently promulgated, revised federal ICF/MR regulations may require many states to intensify spending on ICF/MR services even further. Less well-understood at this point are the ramifications of increased regulatory scrutiny on spending in privately-operated ICF/MRs.

It seems clear that one side effect of the heightened federal scrutiny of ICF/MR services has been to destabilize state developmental disabilities spending. Per diem costs are rising in some states at such a rapid rate that, even with accelerated state efforts to place institutional residents to community-based settings, states are still finding it necessary to pour new dollars into state-operated institutions to meet regulatory requirements. As a consequence, in many states, maintaining ICF/MR certification is increasingly competing for the scarce resources that might otherwise be employed to expand community-based services. Hence, there is growing concern among the states that a Say's Law of MR/DD services has emerged: the high costs of the most restrictive service alternative absorb the dollars that would otherwise be allocated to more satisfactory services.

D. Conclusion

There is no doubt that Medicaid financing of specialized developmental disabilities services played a major role in permitting state service delivery systems to grow very rapidly over the past two decades. It is unlikely that any other source of federal assistance could have played a comparable role. At the same time, this brief recounting of the measurable outcomes of the states' efforts to employ Title XIX funding within their service delivery systems suggests that the time has arrived to reformulate current policies. The effects of current policies and the critical issues they pose are summarized below:

- State/federal Medicaid funding for developmental disabilities services remains overly concentrated on a relatively small number of persons.

The advent of the HCB waiver program provides strong evidence that alternatives to ICF/MR services, in fact, can improve the overall efficiency of state-federal Medicaid spending on behalf of persons with developmental disabilities.

Despite a steady rate of decline in the number of persons residing in large, state-operated facilities, spending for such services continues to increase. While evidence remains scanty, it appears that the net fiscal effect of federal look-behind surveys to date has been to accelerate the rate of spending in ICF/MR facilities.

Painting the current status of nationwide funding for public developmental disabilities services in broad strokes, it seems evident that a financing crisis is emerging. Increasing program costs coupled with growing consumer demands are creating budgetary pressures that have not been addressed constructively at the federal level. Moreover, concerns must be raised about the capacity of states to continue to increase state appropriations to meet the growing cost of ICF/MR services (particularly in state-run facilities) without considerably eroding their capacity to respond to additional consumer demand.

To continue with this theme, 1982 essentially marked the end of the era when states were able to exploit the ICF/MR program to free up state general revenue dollars to support community services. Until approximately 1986, ongoing population reductions in state-operated facilities resulted in a period of relative stability in state institutional expenditures: population reductions permitted state spending to remain fairly constant in real dollar terms. More recently, however, state spending has begun to rise again, despite a continuing decline in institutional populations. Inevitably, one of the consequences of this phenomenon, particularly if it persists, will be a reduced ability on the part of the states to expand community services in response to growing consumer demand.

- Present federal policies also work against such an expansion. In the closed-ended framework of the HCB waiver program, the number of persons who

may be served is limited. Burgeoning consumer demand cannot readily be met in the context of the HCB waiver program.

The variability in how states have employed Medicaid dollars on behalf of persons with developmental disabilities raises questions concerning equal access to needed services nationwide and also renders the articulation of new Medicaid policies extremely difficult.

Finally, it remains to be seen how these thorny issues can be addressed given the federal budget deficit and the fact that Medicaid spending on behalf of persons with developmental disabilities already represents one of the most rapidly growing areas of federal domestic assistance.

CHAPTER IV

PROPOSALS TO REFORM MEDICAID POLICIES

IV. PROPOSALS TO REFORM MEDICAID POLICIES

Over the past several years, the growing recognition of the need to restructure Medicaid policy has spawned a variety of proposals aimed at correcting the perceived shortcomings in current federal policies affecting services to persons with developmental disabilities. The purpose of this chapter is to discuss each of these proposals and other possible alternatives for revamping federal policies, with the aim of helping the reader to understand the potential directions that reform strategies might take as well as the advantages and disadvantages associated with particular options.

Our intention is not to identify which of these specific approaches to Medicaid reform would address the issues and frustrations stemming from current federal policies in the most effective or politically acceptable manner. Each of the various approaches represents a legitimate attempt to resolve enormously complex problems. Assessing the potential effects of each approach offers one means of understanding how difficult it is to accommodate all the concerns that have sparked a strong interest in reforming Medicaid policies.

Given the present policymaking climate in Washington, the potential impacts of each approach on the federal budget will receive special attention in this section. For better or worse, any proposed change in federal Medicaid law affecting persons with developmental disabilities (or, more broadly, any proposed change in federal domestic assistance programs) must run the gauntlet of a federal budgetary process that has, as its principal focus, containing or reducing the impact on the massive federal budgetary deficit. Thus, the feasibility of any reform proposal is inextricably tied to federal budgetary politics.

In the next section of this report, these proposals are examined in detail regarding their potential ramifications for resolving critical issues in several different areas of federal Medicaid policy. In addition, the Appendices A-D of this report provide more detailed information on the contents of several of these proposals.

A. Chafee/Florio

The reform proposal that has received the widest attention is contained in a bill that was introduced by Senator Chafee (R-RI) and Representative Florio (D-NJ) (S. 1673/H.R. 3454) during the 100th Congress. While this bill, called the "Medicaid Home and Community Quality Services Act of 1987", actually represented the third attempt by Senator Chafee in a period of five years to gain Congressional approval of major changes in Medicaid policies affecting persons with severe disabilities, the legislation carried forward many of the major themes that shaped his earlier legislative proposals. It is very likely that this legislation ~ possibly revised somewhat — will be reintroduced when the 101st Congress convenes in January and receive serious consideration by the Senate Finance Committee (the Senate's committee of jurisdiction for the Medicaid program).

Since this legislation has been discussed so extensively (for example, see Gettings, 1988), it is not necessary to recapitulate its major provisions in detail here. [N.B., Appendix A also contains a summary of the legislative history, key provisions of this bill, and related considerations.] Suffice it to say that the Chafee/Florio legislation represents a major attempt to restructure federal Medicaid policies as they affect persons with developmental disabilities. A primary objective of the bill is to maintain the Medicaid program as the principal source of federal assistance for developmental disabilities long-term care services. The intent of the legislation is to carve out a deeper, potentially more secure, niche in Medicaid for specialized DD services. This approach is strongly influenced by the perceived need to tie domestic assistance for persons with developmental disabilities (and, more broadly, severe disabilities) to the "entitlement" features of the Medicaid program as a means

of obtaining more consistent, broad-based funding for community and family support sendees. The fact that Medicaid is a "protected" program under the Gramm-Rudman-Hollings deficit reduction law also is viewed as another advantage in sustaining federal assistance for specialized DD services.

There is no doubt that the legislation addresses critical federal Medicaid policy issues by:

permitting Medicaid funding to be accessed for community and family support services without proving the individual's "need for institutionalization";

proposing a means of establishing a state-level framework for organizing Medicaid-financed programs and services while keeping federal oversight at an appropriate level;

- broadening the array of Medicaid-reimbursable services in a manner consistent with contemporary views on how specialized services can be provided in an ideologically sound and cost-effective manner; and,

providing a fiscal framework that provides significant trade-offs to states in return for continuing to deemphasize services in large facilities.

While the legislation does not attempt to address all the current issues associated with present federal policies (e.g., the inherent conflicts between general Medicaid policy parameters and the organizing logics of state MR/DD service delivery systems; or concerns about the fiscal consequences of current federal ICF/MR policies), it is fair to say that this legislation, on balance, represents a substantial reordering of federal policies under a more satisfactory framework than presently exists. The Chafee/Florio bill would align federal policies with contemporary values and methods of service delivery and, thus, remove a major source of the dissonance in federal-state relations.

At the same time, however, the potential fiscal impact of the legislation underscores how difficult it can be to pursue major reform of federal Medicaid policy in the present federal budgetary environment. The bill's substitute for the "need for institutionalization" (receipt of SSI benefits by persons with severe disabilities), when combined with the minimum array of services that must be offered to eligible persons, would increase federal outlays to an extent that probably would be impracticable in the present climate. By stepping beyond a narrower reform framework that addresses only policy issues within the context of current or projected federal outlays, this legislation triggers extraordinary federal budget scrutiny. Thus, it should be kept in mind that issues involving reform of present federal Medicaid policies encounter substantially different tests, depending on the significance of their potential impact on federal outlays.

For the purpose of the present discussion, the following key points regarding this legislation should be kept in mind:

First, the Chafee/Florio bill would qualify a large number of persons with severe disabilities for Medicaid long-term care benefits. Presently, specialized Medicaid-financed long-term care services for persons with developmental disabilities are furnished to approximately 175,000 individuals. The minimum population that would potentially be entitled to benefits under the Chafee legislation initially would be at least 750,000 persons. In addition, the legislation would expand this entitled population

The legislation stipulates that persons who are found to be eligible for SSI benefits due to a physical or mental impairment that originated prior to age 22 would be eligible for services authorized under the legislation. As discussed in Chapter III, there are approximately 747,000 SSI recipients with mental retardation or "other related conditions."

over time (by increasing the maximum age of onset); and, states could elect certain eligibility options which could further increase the number of persons eligible to receive Medicaid-reimbursable long-term care services beyond SSI recipients. Ultimately, when the legislation was fully implemented, more than 2 million persons with severe disabilities could qualify for services.

Second, the bill's mandatory service array (i.e., the set of community and family support services each state would be required to make available to eligible persons) is likely to result in relatively high service utilization rates. Since coverage of community and family support services would become a basic condition of participation in the Medicaid program two years after enactment of the legislation, no state could afford to opt out of such coverage. Even though nearly every state has elected to cover ICF/MR services under their Medicaid plans, there are a number of reasons why actual utilization of such services will never approach the potential number of persons who might qualify for admission to an ICF/MR (e.g., the reluctance of many families to institutionalize their sons and daughters; the strict capacity controls exercised by states over ICF/MR bed capacity, etc.). The wider array of services mandated by the Chafee/Florio bill would likely spur broader utilization in Medicaid-reimbursable services by persons with severe disabilities. Indeed, this is a basic objective of the bill.

Third, the Chafee/Florio legislation does not substantially alter federal policies governing the provision of ICF/MR services. While the imposition of a cap on Medicaid payments for services provided in large ICF/MR facilities is a key element of the legislation, S. 1673/H.R. 3454 would leave the basis of the ICF/MR program undisturbed. As a consequence, the legislation would not affect the rising costs of such services. Furthermore, by creating a host of possible uses of Medicaid dollars to finance community-based services, the expectation of the bill's sponsors is that the role of large facilities in serving persons with developmental disabilities will continue to shrink, perhaps even at an accelerated pace. It also is worth noting that the Chafee/Florio bill would not place constraints on the establishment of smaller (six-seven beds or less) ICF/MRs.

Fourth, the Chafee/Florio bill seeks to delegate decisions regarding the organization and structure of services to the state level, by mandating that state implementation of the legislation be preceded by the development of a detailed implementation strategy, which is subject to public review and comment. However, there is no assurance that these provisions of S.1673/H.R.3454 will not be amended at some point in the legislative process to authorize a more peremptory federal role. The bill's implementation planning provisions were carefully crafted to limit the administrative role of the Secretary of Health and Human Services in regulating state planning and oversight activities, in order to avoid the problems experienced with the HCB waiver program. Certainly, these elements of the Chafee/Florio bill are at odds with the general climate that is prompting expanded oversight and more stringent federal regulation of ICF/MR and waiver programs. It also must be kept in mind that key supporters of the legislation are not convinced that unfettered state discretion in the management of Medicaid-funded programs will serve the best interests of persons with developmental disabilities.

Fifth, the legislation would not solve one key problem: the inconsistency of the Medicaid means test with the non-income tested disability-orientation of state MR/DD programs. S.1673/H.R.3454 would authorize changes in the Social Security Act that address certain related problems; but, eligibility for services in any particular state would continue to be tied to a state's general Medicaid income/resource test.

Sixth, contained in the legislation are provisions which, in and of themselves, would tend to raise the costs of services. The Chafee/Florio bill seeks not only to broaden the types of services that could be financed through Medicaid and the number and types of persons who would be eligible for such services but also to enhance key services. The provisions regarding case management services, for example, are a case in point. The legislation would require most states to intensify case management services by significantly reducing the average caseload of a case manager.

There is no doubt that the Chafee/Florio legislation would substantially expand the options for financing services to persons with developmental disabilities and other severe chronic conditions through the federal-state Medicaid program. The objectives of the legislation go well beyond changes aimed at permitting current Medicaid dollars to be better utilized. Among the other significant objectives of the legislation are to: (a) increase the number and types of disabled persons who are eligible to receive Medicaid-reimbursable long-term care services; (b) embed in federal statute certain ideological values related to serving this population; and, (c) spell out, in considerable detail, how states should be expected to organize and deliver services.

From the perspective of those who recognize the need for far-reaching changes in current Medicaid policy, the question is not whether the Chafee/Florio bill would authorize such changes but rather is it reasonable to anticipate, given the current federal budgetary environment, that Congress and the White House would be willing to accept such a potentially costly strategy for reforming Medicaid policy.

During House hearings on H.R.3454 in September 1988, the Congressional Budget Office (CBO) estimated that the legislation would result in a net reduction of federal budget outlays for Medicaid reimbursable DD long-term care services of \$730 million during the five years following enactment (see Appendix A for a more detailed discussion of CBO's estimates). CBO based its findings on its assessment that the cap on Medicaid payments for services in large ICF/MRs would take hold immediately while the additional services authorized under the bill would not be instituted until the states completed their implementation plans and developed the required additional service capacity. Over the five years covered by the CBO estimate, reductions in payments for large ICF/MRs would offset growing federal payments for community and family support services and increased federal/state administrative expenses.

However, estimates prepared by the Reagan Administration attributed a major fiscal impact to the legislation (ASPE/HHS, 1988). The Administration anticipated an immediate increase in federal Medicaid spending of \$700 million in the first year following enactment (a jump of 17 percent over estimated federal outlays under current law). In the second year following enactment and thereafter, the Administration expected an annual impact of approximately \$13 billion in increased federal outlays (or a 29 percent increase over levels projected under current law). The potential impact of the proposed freeze on payments to large ICF/MRs also was substantially discounted. At the same time, the Administration expected the states to rapidly increase Medicaid claims by qualifying under their Title XIX programs existing community and family support services currently financed with state/local dollars, by noting that states have a large reservoir of unmatched state funds that could serve as matching dollars to immediately increase Medicaid claims.

While these estimates of the potential fiscal impact of S.1673/H.R.3454 obviously are widely disparate, the principal source of disagreement is the differing assumptions concerning the near term responses of the states to the proposed legislation. Over an extended period, CBO, in fact, estimated a net positive impact on federal outlays should the Chafee/Florio bill be enacted. The bottom line is that any approach to Medicaid reform that ultimately may result in a ten-fold increase in the number of eligible recipients of long-term care services is likely to cause a sizable escalation in both federal and state costs.

In the context of enacting new legislation, it is important to keep in mind that the exact impact of a legislative proposal on the federal budget is usually less important in gaining passage than securing a consensus of the House, the Senate, and, to a lesser extent, the Executive Branch that any additional costs the particular legislative proposal may engender are anticipated in future budgetary projections. With respect to the Chafee/Florio legislation, it is clear that the Reagan Administration did not agree with CBO's preliminary assessment that the bill would not have a major, short-term budgetary impact. While there is no way of predicting the views of the Bush Administration or key Congressional actors, it seems highly unlikely, given the expanded eligibility and coverages contemplated under the legislation, that the Chafee/Florio bill will ever be viewed as budget neutral.

Furthermore, it must be pointed out that CBO's conclusion regarding the fiscal impact of the Chafee/Florio bill is highly reliant on the enactment of the institutional spending limitation that was proposed in S.1673/H.R.3454. In the absence of such a limitation, the legislation would entail a sizable increase in Medicaid spending according to CBO's estimates. To the degree that such an allowance must be made, the legislation must compete with all other proposals for new spending as well as running head long into efforts to reduce the deficit. The proposed cap runs counter to the House's long-standing opposition to capping any element of the Medicaid program and has been opposed by several interest groups. Most recently, the National Association of State Mental Retardation Program Directors (NASMRPD) has expressed its unwillingness to accept such a cap given the apparently uncontrollable rate of increase in ICF/MR operating costs in the wake of intensified federal oversight activities.

Furthermore, under the Gramm-Rudman-Hollings spending control mechanism, a new program that has a substantial fiscal impact can have far-reaching consequences, not the least of which is that it creates the potential for sequestering funds in other programs. In addition, a major increase in spending in one area of Medicaid spending substantially reduces the chances that other Medicaid agenda items can be pursued by Congress or the Administration. Thus, an increase in spending for MR/DD services competes with a host of other agenda items, including widening the availability of non-institutional services for elderly persons or broadening overall Medicaid coverage of children. Barring a major shift in national priorities away from containing the federal budget deficit, the Chafee/Florio legislation, in its present form, may pose too great a danger of exacerbating the deficit. Unless the fiscal ramifications of the bill are resolved, it seems highly unlikely that the legislation could be enacted, given the issues it poses for managing overall federal Medicaid spending.

If the potential cost of the legislation constitutes a major impediment to its passage, the logical course of action would be to modify it in ways that would lower the fiscal impact. However, it is not clear the legislation could be modified to yield a smaller fiscal impact without seriously eroding its base of support. More aggressive containment of federal payments for institutional services, for example, would intensify the opposition of public employee unions, parents of institutional residents, and possibly other interest groups. Furthermore, state MR/DD agencies have already made known their reservations concerning the legislation's cap due to escalating ICF/MR costs.

Testimony by James Toews before the House Subcommittee on Health and the Environment, September 20, 1988.

Under the Gramm-Rudman-Hollings deficit reduction mechanism, Medicaid is a "protected" expenditure category; i.e., if the projected deficit exceeds the predetermined target for any particular year, the Medicaid program is exempted from the "automatic" spending cuts that are required to be made through sequestering a percentage of appropriations in non-protected areas of the federal budget in order to meet the deficit target. A major increase in Medicaid spending may trigger sequestering dollars in other elements of the federal budget; avoiding that outcome enters into the Congressional calculus when considering changes in the Medicaid program.

Narrowing eligibility standards would certainly lower the fiscal impact estimates, but it also would exclude categories of potential recipients from the benefits of the newly authorized program. For example, if the provision for gradually increasing the age of onset of disability were to be stricken from the Chafee/Florio bill (thus limiting eligibility to persons with disabilities originating in childhood), the long-term fiscal impact of the legislation would be considerably reduced. However, persons with disabilities originating in young adulthood to mid-age would not be entitled to receive community and family support services and, consequently, organizations that represent such constituencies, understandably, would be quite upset.

Similarly, limiting the types of Medicaid covered services would undermine the basis of the bill: namely, allowing greater flexibility in the types of services provided in order to promote community living opportunities. In summary, the fiscal compromises necessary to gain passage of a scaled-down version of the Chafee/Florio bill could easily destroy the coalition that has been formed to secure its passage.

In addition, despite the apparent widespread support of this legislation in Congress, it would be a mistake to underestimate the strength of the opposition. It is clear that public employee unions will remain opposed to the bill, regardless of provisions designed to protect public sector jobs. Besides, if the employee protection provisions of the legislation become too strong (e.g., tantamount to job guarantees), some state governments may conclude that the fiscal consequences cannot be tolerated and oppose the legislation. It also is clear that the step taken in S. 1673/H.R. 3454 to weaken the institutional downsizing/closure provisions of the earlier Chafee proposals has not mollified the opposition of institutional parent groups. Their strong opposition to the legislation is capable of derailing any bill, no matter how widespread its support in the rest of the MR/DD community.

Finally, it must be recognized that key actors in both the House and the Senate remain opposed to the legislation for reasons that have little to do with program ideology or their level of satisfaction with current federal policies. It is exceedingly unclear what, if any, changes can be made in the legislation that would gain the support of these key Congressional actors.

Consequently, the prospects for the passage of the Chafee/Florio bill during the 101st Congress are far from certain, despite the large number of House and Senate members who co-sponsored the legislation in 1987-88. The political and economic necessity of containing the federal budget deficit stands as an enormous barrier to the bill's adoption. The results of the recent election are not likely to have a substantial impact on the way in which the deficit problem is viewed by Congress or the Executive Branch.

The foregoing discussion, of course, does not mean that the Chafee/Florio approach is infeasible or undesirable. It does suggest that it, or other approaches that contemplate expansion of federal long-term care benefits to persons with developmental disabilities, will encounter tough problems when it involves a major increase in federal outlays.

B. The Waxman Proposal

On August 11, 1988, Representative Henry A. Waxman (D-CA) introduced a bill (H.R. 5233) that would authorize less sweeping changes in federal Medicaid policy as it impacts on persons with developmental disabilities. The "Medicaid Quality Services to the Mentally Retarded Amendments of 1988", nonetheless, would have made substantial changes in current law. Appendix B outlines the provision of this legislation in greater detail as well as other features of the legislation. Since the Waxman bill was only introduced late in the 100th Congress and, thus, has not received the same level of discussion as the Chafee/Florio legislation, we will spend some time explaining its key provisions. The purpose of this discussion is to pinpoint the relationship of this legislation to the broad issues that undergird the need for Medicaid reform; we also will describe the potential fiscal implication of the legislation. It should be noted that Representative Waxman plans to reintroduce his legislation during the 101st Congress, but it may contain substantial modifications.

The Waxman bill essentially reflects three lines of thinking. First, broadened Medicaid coverage of community services — in the form of a new, optional state plan coverage, called "community habilitation services" - is proposed (partly in direct response to the Chafee/Florio legislation); but, unlike the Chafee/Florio bill, the Waxman legislation would leave it to the states to decide whether or not to incorporate these services in their Medicaid state plans. In other words, H.R. 5233 would maintain the long-standing Title XIX policy that states are free to select (and limit) Medicaid benefits other than for a core set of acute care (e.g., hospital and physician) services.

Second, the Waxman bill would tie the receipt of federal payments for Medicaid-reimbursable DD services more closely to state compliance with federal standards. Rather than restricting the level of federal oversight of state programs, the bill would: (a) enact into law the principal provisions of revised ICF/MR standards and empower the Secretary to review the appropriateness of current and future placements in ICF/MRs; (b) authorize the Secretary to promulgate federal standards governing the provision of residential services furnished under a state's HCB waiver program or as an optional community habilitation service; and, (c) authorize the Secretary to develop and the states to enforce additional performance measures governing all forms of community habilitation services. These quality assurance provisions reflect a strong presumption that federal participation in the costs of Medicaid-reimbursable services must be accompanied by adequate guarantees that such services meet basic national standards.

Third, the legislation would create national standards for the determination of eligibility of persons with developmental disabilities to receive Medicaid-reimbursable DD long-term care services. The Secretary of HHS would be authorized to develop criteria governing the classes of persons with developmental disabilities who could be served in ICF/MRs. The bill would require the Secretary to promulgate explicit criteria that the states would have to apply in evaluating the eligibility of all individuals to be admitted, or continue to reside in, an ICF/MR. These standards would have to be issued within a year of enactment of the legislation. Hence, H.R. 5233 would clearly define who may receive Medicaid-reimbursable long-term care services.

While the Waxman bill addresses other areas of federal policy (including permitting a state's governor to assign Title XIX administrative responsibilities to the state MR/DD agency and prohibiting HCFA from imposing the Medicare upper limit test on payments for ICF/MR services), the discussion here will focus on the three areas identified above.

1. Community Habilitation Services

Representative Waxman's intention in proposing that "community habilitation services" be added as an optional state Medicaid plan coverage is to continue the traditional approach Congress has used in altering federal Medicaid policies. As discussed in Chapter II, the Medicaid program was not conceived of as a federal health care program, but rather as a means of helping states to pay the cost of meeting the health care needs of low-income Americans. While Medicaid law mandates that participating states provide a minimum array of acute health care services to AFDC and SSI recipients, it is structured to permit the states considerable latitude in shaping their programs by selecting optional services from a menu of alternative coverages authorized under Title XIX of the Social Security Act. States are free to adopt or not adopt such coverages and establish their own limitations on the utilization of such benefits. With certain exceptions, changes in Medicaid policy historically have occurred by making new coverages available to states that desire to extend the scope of their Medicaid programs, rather than by mandating such coverages. This approach can be contrasted with the approach used in the Chafee/Florio bill, which would require all states to provide a minimum array of community and family support services to eligible persons with severe disabilities. In this sense, Representative Waxman's proposal represents a "mainstream" approach to altering federal policies. Congress, for example, adopted a similar

approach in adding "targeted case management" services as an optional state plan coverage in 1986.

From a fiscal perspective, the addition of community habilitation services as an optional state plan coverage would have an uncertain impact. There is no doubt that "community habilitation services", as defined in the bill, would give a state the potential to cover a scope and range of services that could be nearly as broad as those which would be authorized under the Chafee/Florio legislation. Habilitation services are an integral component of nearly every service furnished to persons with developmental disabilities and, by their very nature, tend to be among the more expensive services in any state's community service delivery system. In addition, the bill would permit states to cover prevocational and supported employment services furnished to any eligible individual, thus broadening the coverage of such services (which are presently restricted to previously institutionalized participants in HCB waiver programs).

At first glance, it would appear that the fiscal impacts of this legislation might parallel or even exceed those of the Chafee/Florio bill. There is no doubt, for example, that many "mainstream" community-based services presently offered by states would fit comfortably within the framework of community habilitation services and, hence, states could increase their claims for Medicaid reimbursement significantly. In addition, H.R. 5233 would not limit payments to larger ICF/MRs and, thus, such a cap would not offset the fiscal impacts of expanded federal support for community-based services, as would be the case under the Chafee/Florio bill. In addition, since the provisions of H.R. 5233 closely parallel the scope and range of services that most states furnish as part of their HCB waiver programs, the legislation would offer such states an opportunity to exchange the spending and caseload limitations that are currently imposed on HCB waiver programs for a broader-based means of claiming federal Medicaid reimbursement.

At the same time, however, it is important to point out three critical elements of the Waxman bill that could result in an impact significantly lower than the Chafee/Florio legislation:

First, eligibility for community habilitation services is more tightly defined than in the Chafee/Florio bill. The Waxman bill would require a state electing to cover community habilitation services to make such services available only to persons with mental retardation and related conditions who are categorically eligible for Medicaid. Individuals whose income and/or resources may disqualify them for categorical Medicaid eligibility would be required to meet an additional test — i.e., they would have to be found to otherwise meet ICF/MR level of care criteria (in other words, "need active treatment"). On the whole, the thrust of these provisions, coupled with an unwillingness to extend eligibility to the broader population of "persons with severe disabilities", would result in a smaller population of individuals being potentially eligible for services under this legislation, compared to the Chafee/Florio bill. Obviously, over the long-term, these differences in target populations would be accentuated because of the provision in S.1673/H.R.3454 calling for a gradual increase in the age at which the origin of a person's disability would qualify him or her to receive community and family support services.

Secondly, by authorizing community habilitation services as a state option, H.R. 5233 adds another element of uncertainty, since it is impossible to predict how many states would elect to cover such services under their Medicaid plans; consequently, it is extremely difficult to estimate the fiscal impact of the proposed new coverage. While superficially it might appear that most states

would find it highly advantageous to incorporate coverage of community habilitation services into their state Medicaid plans, it is unclear exactly how many actually might do so and at what pace. Since the definition of community habilitation services would be synchronized with a revised definition of habilitation services under the HCB waiver program, one might speculate that states which administer HCB waiver programs would welcome the opportunity to elect an optional state plan coverage in order to escape the caseload and expenditure limitations imposed on waivers by HCFA. At the same time, however, it must be kept in mind that — at least to date -- only 10-12 states have chosen to cover "targeted case management services" under their state Medicaid plans despite the fact that case management services are an integral element of every state's MR/DD service delivery systems. To a degree that is largely unpredictable, states usually are cautious in adding any new benefit to their state Medicaid programs.

Finally, since community habilitation services would be authorized as an optional coverage, states would have the latitude to establish service limitations that would restrict the frequency, scope, and duration of services furnished to eligible persons. While the number of persons who would be eligible for community habilitation services is smaller than that the target group delineated under the Chafee/Florio bill, it is nonetheless larger by at least a factor of five than the number of persons who presently receive Medicaid-financed DD services. Generally, states have attempted to employ restrictions on Medicaid-funded optional benefits as a means of avoiding rapid increases in utilization that would outstrip their capacity to finance services. There is a strong likelihood this would occur if community habilitation services were authorized as an optional Medicaid coverage. States might seek to maximize federal payments, but many states probably would impose controls to prevent runaway growth in spending and utilization.

In short, while conceptually the Waxman bill could have a large fiscal impact, its actual impact probably would be substantially less than the Chafee/Florio bill, at least in the near to mid-term. Authorizing community habilitation services as an optional state plan coverage, however, in the longer term, might be expected to have effects paralleling those of another optional state plan coverage: ICF/MR services. At the bottom-line, any estimate of potential impact must be conjectural, since it would depend on how fifty-one jurisdictions respond to the availability of a new optional Medicaid state plan coverage.

To expand somewhat on the experience with the "targeted case management" services option, it is clear that a host of factors have affected the pace at which states have elected this option. Initial HCFA policy guidelines, issued after Congress enacted legislation authorizing this service in April, 1986, posed certain difficulties for some states. Statutory provisions (since corrected) created other problems with regard to state laws that restricted the types of entities that could furnish case management services. In some states, selection of this optional coverage posed operational problems. In other states, selection of the option has been stymied by general concerns about the fiscal impacts of adding an entitled service to state Medicaid programs that are already viewed as out of control. The main point to keep in mind is that offering the states the option of adding additional state plan coverage will trigger different responses in each of the states; it is unreasonable to expect, therefore, that all or most states will rapidly adopt a new state plan option no matter how attractive it might be for state MR/DD service delivery systems.

Shortly following the introduction of H.R. 5233, the Congressional Budget Office produced spending estimates that fell into what is considered the "deficit dust" range of fiscal impacts. According to CBO, Representative Waxman's bill could be expected to increase federal Medicaid spending by only \$25 - \$30 million during each of the three years following enactment. CBO's analysis based these very modest projected increases in spending on the assumptions that: (a) only 7-8 states would choose to cover community habilitation services (based on experiences with states electing to cover other newly offered state plan options; and, (b) the "need for institutionalization" test of eligibility would substantially reduce the number of individuals who could qualify to receive such services (see Appendix B for a more complete discussion of CBO's estimate of H.R.5233's fiscal impact). The Reagan Administration officials did not comment on these estimates, although it seems likely that they would have attributed a considerably higher fiscal impact to H.R. 5233.

Beyond considerations of fiscal impact, it is important to examine the proposed addition of community habilitation service coverage on its own merits. First, H.R. 5233 defines such services in a way that parallels the types of services most states furnish under HCB waiver programs. Indeed, the bill's definition of the term "community habilitation services" is a somewhat modified version of the definition of "habilitation services" that appears in current law governing the HCB waiver program. In that sense, the proposed coverage is closely aligned with the array of services that three-quarters of the states have elected to provide through waiver programs. If the extensive state utilization of the HCB program is an indicator of a preferred approach to delivering Medicaid-reimbursable DD long-term care services, then the proposed optional coverage and state practice are well-aligned.

Second, the Waxman proposal would eliminate "need for institutionalization" as an eligibility criterion for receipt of Medicaid-reimbursable DD services for the large majority of Medicaid-eligible persons with developmental disabilities (i.e., those who are entitled to receive SSI and AFDC benefits). Unfortunately, the "need for institutionalization" would remain a test, of eligibility for those who are not categorically eligible for Medicaid benefits.

Third, it is important to note that the Waxman bill would not link the provision of community habilitation services directly to residence in a federally-defined facility. Services furnished to an eligible person with developmental disabilities could be provided in any setting. Thus, community habilitation services would represent a means of removing the oft-criticized "facility-based" bias of federal Medicaid policies and permitting community-based services to be organized under a "supportive services" construct, without sacrificing federal financial participation.

The dubious merits of imposing the "need for institutionalization" test on non-categorically eligible recipients can be understood by examining the circumstances that would cause a person to fail Medicaid's categorical means test. For example, a large number of persons (approximately 300,000) receive OASDI (Social Security) benefits (usually as a dependent, based on the earnings record of a parent), but the amount of such benefits excludes them from receipt of SSI payments. In many states, these persons cannot qualify for Medicaid services solely based on income, even though their degree of disability is similar to that of SSI recipients. The second critical group are children living at home who are denied SSI eligibility due to parental income. Again, circumstances unrelated to their degree of disability impede the extension of Medicaid coverage to these children. From a general policy perspective, imposing a secondary test of eligibility on individuals with similar levels of disability to SSI recipients does not appear to be appropriate.

On the other hand, related quality assurance proposals contained in the Waxman legislation (and discussed in more depth below) would create significant uncertainties for the states. In addition, there is no doubt that leaving the coverage of community habilitation services on an optional basis could result in the same degree of spotty availability of such federally-financed services, state-to-state, that led to the specification of a minimum service array in the Chafee/Florio legislation.

2. Quality Assurance

H.R. 5233 poses a simple proposition to states: in return for Medicaid coverage of community habilitation services, a state must agree to abide by federally-defined standards governing the provision of such services. The recent course of federal administration of Medicaid-reimbursable DD services, however, makes the states rather wary of this proposed quid pro quo. In addition, the legislation would make important statutory changes in the oversight of ICF/MRs.

In many respects, Representative Waxman's proposals have been influenced by Congressional experience with the Medicaid nursing facility program as well as federal look-behind surveys of ICF/MRs. With regard to nursing facility services, in recent years enormous problems have emerged in assuring that such services were of acceptable quality. Congress reacted to those problems by defining more clearly ~ in the Omnibus Budget Reconciliation Act of 1987 — its expectations regarding the scope and quality of services that must be furnished in Medicaid-certified nursing facilities. While the evolution of this legislation was marked by Congressional consternation with the Secretary's exercise of HHS/HCFAs regulatory responsibilities, Congress recognized that, if national standards were to be more tightly defined, it had no choice but to rely on HCFA to exercise closer federal oversight of the delivery of such services. Thus, HCFA's regulatory and enforcement responsibilities were spelled out in greater detail to prevent the neglect that Congress believed permitted problems in nursing facility services to reach the proportions they did (Gettings et al., 1988). The ICF/MR look-behind experience has suggested to some members of Congress that parallel problems exist in the provision of Medicaid-reimbursed DD long-term care services. Hence, the Waxman bill proposes the creation of a stronger federal oversight role whenever Medicaid dollars are employed to finance ICF/MR and community habilitation services to persons with developmental disabilities.

The influence of Congressional experience with the nursing home program is most readily apparent in the provisions of H.R. 5233 which would delineate in law the "conditions of participation" for ICF/MRs (which also are redesignated as "habilitation facilities") and empower the Secretary to impose a variety of sanctions in the event of non-compliance. This proposed step has two results: HCFA's current ICF/MR regulations would be embedded in statute and HHS would have stronger oversight powers.

While the proposed legislation parallels the principal provision Congress adopted in addressing the perceived problems in nursing facilities, it diverges from the process that led to the adoption of those provisions. It should be kept in mind that the nursing home reform provisions of OBRA-87 were preceded by extensive study of the key factors needed to promote the delivery of effective nursing facility services. With regard to ICF/MRs, no similar study has been undertaken. Rather, regulations developed by HCFA, without the benefit of substantial research into the most effective methods of furnishing facility-based habilitation and related services, would be adopted in statute. To the extent that the current ICF/MR standards and their enforcement by federal and state survey agencies are based on questionable premises regarding the most appropriate and effective methods of delivering such services, the problems posed by these regulations would become a permanent feature of federal law.

While it would be foolhardy to suggest that avoiding the statutory enactment of these regulations would increase the likelihood that HCFA would promulgate improved standards in the future (after all, HCFA's June 3, 1988 revised regulations replaced a fourteen year old set of rules and took six years to promulgate), the prospect of Congress enacting the present standards and arming HCFA with additional enforcement tools could exacerbate the negative ramifications of the look-behind initiative.

By granting the Secretary the authority to establish regulations governing residential services furnished under state HCB waiver programs and develop broader-based regulations spanning all community habilitation services, the Waxman bill would establish, for the first time, a federal presence in regulating community services provided in settings that heretofore have been regulated solely by the states. Under the HCB waiver program, for example, a state must assure that certain health and welfare protections will be provided to waiver recipients; states have broad latitude in defining the standards necessary to demonstrate that such an assurance will be met. Apart from the so-called Keys Amendment provisions governing residences in which SSI recipients reside (Section 1616 (e) of the Social Security Act), all "non-institutional" community-based services provided under Medicaid-financed HCB waiver programs are regulated by the states.

While these proposed provisions can be viewed as a simple assertion of a federal right to certain guarantees that services provided with federal dollars conform to basic standards, there are at least three troublesome dimensions in this area of the proposed Waxman bill:

First, the authority that would be granted the Secretary is relatively broad. Such authority, in the hands of a hostile Administration, could lead to the promulgation of standards aimed less at promoting quality services than impeding states from increasing the claims for federal reimbursement. In this respect, there are potential parallels with the states' experiences under the HCB waiver program.

Second, there is no reason to believe that regulations that might be adopted by HCFA will not parallel, in their basic aims and scope, the revised ICF/MR regulations. While such standards obviously could not rely on "active treatment" as a framework to construct federal standards, the tenor of recent regulatory activity clearly has been to promulgate highly prescriptive standards. The fundamental issues in this area involve the degree to which HCFA might impose: (a) clinical standards on the provision of community habilitation services; (b) excessive requirements for client oversight and supervision; and, (c) facility standards that would create problems in locating residential services in integrated living arrangements for persons who receive habilitation services.

Third, federal community service standards could result in the same rapid escalation in the costs of services that has been experienced in the ICF/MR program. To the extent that this would occur, state MR/DD budgets would be even more vulnerable to destabilization — an outcome that could lead state policymakers to reduce the range and scope of available community services.

At least with respect to community residential service standards, there is no provision in the Waxman bill that would direct the Secretary to investigate the types of standards that might prove to be most effective. While the Secretary is authorized to undertake such research prior to implementing more general community habilitation service standards, the legislation offers HHS/HCFA little

guidance regarding the expected content or aims of such standards. It is perhaps instructive to note that the guidance that is contained in the legislation parallels, almost exactly, the framework for standard setting proposed under the HHS Medicaid reform proposal. As will be discussed in the next section of this chapter, this framework has the potential of federalizing quality assurance for community-based services.

On the whole, then, these dimensions of H.R.5233 are particularly troublesome. While a federal oversight role is to be expected whenever federal dollars are used to support services, there is an undeniable danger that the negative side-effects of federal regulation of ICF/MRs (i.e., rising service costs; the imposition of a rigid service delivery model; and federalization of standard setting) will be imported into community-based services for persons with developmental disabilities. The potential effects of such federal intrusion lead many states to decide not to cover optional community habilitation services under their state Medicaid plans; in addition, the imposition of federal residential service standards in HCB waiver programs could place states which operate such programs in a Catch-22 situation of rising service costs within a capped federal funding structure.

3. Eligibility for Long-Term Care Services

Finally, the legislation would empower the Secretary of HHS to develop criteria governing the placement of persons with developmental disabilities in ICF/MRs. In the context of current federal law, these criteria also would govern who may be served in an HCB waiver program.

The rationale given by Mr. Waxman for including these provisions in H.R. 5233 is to assure that only persons who require the intensive array of services provided by an ICF/MR are admitted to and permitted to remain in such a facility. Since the legislation also would repeal existing statutory requirements for a utilization review program and an annual physician recertification of the eligibility of ICF/MR residents, the contention is that a substitute procedure is necessary to prevent inappropriate placements and unnecessarily prolonged residence in such facilities. As has been discussed earlier, however, the promulgation of stringent Secretarial criteria governing eligibility for ICF/MR services could have substantial consequences in many states. A narrowing of eligibility for ICF/MR services could: (a) lead to the displacement of many current residents; and, (b) result in the denial of eligibility for HCB waiver services of current program participants as well as persons who might be displaced from ICF/MRs. Given this type of outcome, a state would have little choice but to amend its state Medicaid plan to select community habilitation services. The fundamental danger of this provision is that it might be enacted (as part of the provisions establishing expanded statutory requirements governing ICF/MR services) but the other, potentially more beneficial provisions of the bill (including authorization for coverage of community habilitation services) may fall by the wayside due to their potential fiscal impact.

The overarching problem with granting the Secretary unfettered authority to establish ICF/MR eligibility criteria is that an Administration bent on containing federal outlays could promulgate stringent criteria in order to reduce federal outlays. While undoubtedly such an effort would be greeted by protests from affected states and ultimately might prompt corrective Congressional action, the end result still might be a narrowing of the number of persons eligible to receive Medicaid-reimbursable long term care DD services.

Beyond the dangers posed by placing this authority in the hands of a hostile Administration, the proposal brings to the fore the full array of issues associated with existing federal policies in this area. Again, tying eligibility for specialized Medicaid-reimbursable DD services to eligibility for the most restrictive type of service setting fundamentally skews the organization and delivery of specialized DD services. The problems associated with the "need for institutionalization" test

become more pronounced to the extent that a more stringent test of eligibility for admission to, and continued stays in, an ICF/MR is applied.

4. Summary

Given Representative Waxman's position as chair of the House subcommittee which exercises legislative jurisdiction over the Medicaid program, the directions set forth in H.R. 5233 cannot be regarded lightly. This bill was drafted in response to his criticisms of the Chafee/Florio legislation and provides important clues to the parameters he and other House members would impose on legislation affecting current Medicaid policies.

The Waxman bill adopts an approach to Medicaid reform that is significantly different than the one proposed in S. 1673/H.R. 3454. Rather than Unking reform to an attempt to assure that all states provide a minimum array of services to eligible persons, H.R. 5233 would permit states to elect or not elect to include the coverage of community-based services under their Medicaid plans. The proposed role of the federal government in overseeing both ICF/MR and community-based services provides an important signal of the seriousness Congress attaches to assuring that Medicaid-reimbursable services meet minimum standards.

As with the Chafee/Florio legislation, it seems clear that the Waxman bill would address key issues related to current federal Medicaid policies affecting persons with developmental disabilities. At the same time, other elements of the bill are troublesome and may accentuate existing problems.

The prospects that this legislation (or a modified version) might be adopted by 101st Congress are far from clear. The fiscal impact of the proposed optional community habilitation services coverage may be less threatening than the array of services that would be mandated and permitted under S. 1673/H.R. 3454, but still could affect the prospects of Congressional adoption of H.R. 5233. In the present fiscal environment, the concurrence of the Senate and the White House in any appraisal of fiscal impact will be important; whether such concurrence in fiscal impact of H.R. 5233 could be obtained is impossible to predict.

C. THE APSE/HHS Proposal

While not surviving the Reagan Administration's review of proposals for inclusion in the President's final, FY 1990 budget request to Congress, a legislative reform plan fashioned by a special working group, established by the Secretary of Health and Human Services to address current problems in Medicaid policies affecting persons with developmental disabilities, deserves discussion. First, this proposal furnishes clues as to how HHS officials view key policy issues and how they might be resolved. Second, the approach adopted by the working group, operating under the auspices of the Assistant Secretary for Planning and Evaluation (ASPE), serves as a counterpoint to attempts to reform Medicaid policies by proposing instead to extract long-term care services for persons with developmental disabilities from Title XIX and give them their own special niche in federal statute. [N.B., see Appendix C for a more complete discussion of the evolution of this proposal and its principal provisions.]

It also must be noted that, despite the considerable amount of time it took the ASPE/HHS work group to develop even a general proposal, it is literally impossible to evaluate the resulting plan with any precision because the proposal represents general concepts rather than precise legislative provisions. Nonetheless, the salient points of the ASPE/HHS proposal are as follows:

- Medicaid funding for existing specialized DD services (ICF/MR and HCB waiver services) would be terminated. In addition, the use of Medicaid dollars to support daytime services, personal care, and nursing facility

services furnished on behalf of persons with developmental disabilities would be terminated.

The dollars currently budgeted for the foregoing programs would be transferred to a formula-based grant-in-aid program that would be entirely separate from the Medicaid program. States would be held-harmless with respect to their present levels of federal assistance for these services; furthermore, all states would receive increases in their federal grant allocation based on changes in inflation and population during subsequent years. States which presently utilize Medicaid financing at a rate less than national norms also would receive additional payments designed to help equalize the distribution of federal support for long-term care services among the states.

The total dollars flowing to all states would be regulated to achieve a budget neutral outcome - i.e., the limitation on total spending would be structured to support approximately the historical rate of increase in ICF/MR and HCB spending. States which utilize Medicaid financing at a rate greater than the national average would experience a decline in the rate of growth of federal assistance. Under this proposal, any dollars remaining after the award of base allocations to all states, adjusted each year for changes in inflation and population, would be utilized to equalize federal payments among the states on a per capita basis. In particular, these dollars would be distributed to states that presently utilize Medicaid funding to support MR/DD services at a rate below less than the national average for all states.

States would be required to provide a minimum array of services to persons who are severely to profoundly disabled. This minimum array would include case management, respite care, residential, and "developmental/vocational" services.

States would be required to provide services to all severely and profoundly retarded persons as well as persons with comparable levels of disability as a result of related conditions. HHS/ASPE estimates that 450,000 persons (270,000 adults and 180,000 children) nationwide would be included in this entitled target population. In addition, states could, at their option, cover other persons with mental retardation and related conditions and/or add services to the required minimum array. The federal government, however, would not share in the costs of services beyond the state's fixed grant allocation.

Eligibility for services would not be means-tested. The proposal provides, however, for recipient/family participation in meeting the costs of services to an unspecified extent.

The proposal permits federal grants-in-aid to be administered by the state MR/DD agency. At the same time, however, there are indications that the HHS/ASPE proposal would specify that services must be vendorized through other public and private provider agencies.

The HHS/ASPE plan calls for replacing existing federal regulations with a set of "federal core standards." While the expressed intent of the proposal is to have such standards serve as broad benchmarks for state quality assurance efforts, the proposal also includes provision for federal oversight activities that would be akin to HCFA "look-behind" reviews of ICF/MRs. In this area, the proposal contains the seeds of a more intrusive federal role in quality assurance, at least in community-based services.

While this proposal has been under development for well over a year, it has been widely discounted in Washington. One point of view is that it is merely a more sophisticated version of the Reagan Administration's long-standing policy objective of capping the Medicaid program. Since the proposal would prevent further acceleration in federal payments for specialized DD services, it also is viewed as non-responsive to the demands of the disability community for broader access to Medicaid-financed services.

Nonetheless, the HHS/ASPE plan is worth examining because many of its provisions do, in fact, address root causes of the current dilemmas surrounding Medicaid financing of services for persons with developmental disabilities. In particular:

The proposal to eliminate an economic means tests as a basis of eligibility would establish a closer alignment between current state practices and federal policies. Basing eligibility solely on the nature and extent of an individual's disability is potentially a sounder approach than the present "need for institutionalization" test.

States would be granted considerable flexibility in determining which services are needed and should be provided. For example, vocational services could be furnished without sacrificing access to federal financial support.

The proposed termination of the ICF/MR program would remove the substantial influence this program, with its "active treatment" service paradigm has had on qualifying services for federal Medicaid financing. Removing "active treatment" as the defining characteristic of MR/DD services that qualify for federal funding might offer states an opportunity to dampen the rapid rise in service costs by permitting the wider use of "supportive services" models.

Permitting the state MR/DD agency to administer federal funds would solve the problems associated with the present bifurcation of system management under the Medicaid program in many states.

The proposal would permit states to give local communities a broader role in planning and managing MR/DD services than generally can be accomplished via present Medicaid funding arrangements.

On the other side of the coin are the following considerations:

Even under the "budget neutral" approach proposed by ASPE/HHS, it is by no means clear that the flexibility granted the states to employ federal dollars to support a wide range of services will permit them to achieve sufficient efficiencies to offset the additional costs of entitling 275,000 more people to services. The proposal is based on the unverified assumption that the combination of greater efficiency in service delivery and existing state DD and special education programs will permit the current federal dollars which support 175,000 persons with developmental disabilities to be repackaged to support the 450,000 persons who would be entitled to services under this proposal.

It must be kept in mind that achieving greater efficiency in service provision would require substantial reconfiguration of services; in most states, such reconfigurations could only be accomplished over an extended period of time. Thus, even under the most optimistic set of assumptions, it is unclear when most states could be expected to reap the benefits of improved service delivery. Undoubtedly, the impact of such an entitlement would vary substantially from state-to-state. States with broad-based service delivery systems would experience considerably less impact from this

proposed entitlement than states that presently face long-waiting lists for services.

While the grant allocation methodology outlined in the HHS/APSE plan acknowledges that some special allowances need to be made for states with lower than average rates of Medicaid utilization, the methodology falls far short of assuring parity. States with low initial allocations could only expect to approach parity over an extended period of time. Thus, states that today receive relatively low levels of Medicaid assistance would face the same requirements as states which have higher levels of federal financial participation in MR/DD services. Since the proposal contains no "phase-in" provisions linked to changes in federal allocations, federal funding and federal requirements would be malaligned.

In addition, the proposed formula for measuring "need for additional" assistance is imperfect at best. The methodology uses a single measure (per capita Medicaid spending for specialized DD services) to determine need. No single measure, however, is likely to equitably represent the "need for additional assistance."

The proposal does not address a critical question: if funding is placed on a formula grant basis, what safeguards will be provided that the formula would not be adjusted in future years to reduce grant supports to states? Today, Medicaid financing is protected from Gramm-Rudman-Hollings budget reductions. Would this new grant be similarly protected and would grants to states truly be placed on an entitlement basis? In the absence of proper safeguards, future funding could follow the same course as federal funding of P.L. 94-142: a diminishing proportion of federal assistance over time with no diminution in the requirements, and related funding obligations imposed on states and local jurisdictions. Social services aid to the states under Title XX of the Social Security Act is another example of the vulnerability of federal entitlements. Although the program was originally established as a secure basis of federal assistance to states in meeting the social services needs of vulnerable citizens, the authorization level for the program was sharply reduced in FY 1981 and never fully restored to its pre-1981 level; furthermore, Title XX aid has remained static over the past five fiscal years, while the costs of delivering such services have continued to increase.

The "quality assurance" mechanisms in the HHS/APSE plan also are troublesome. While they are portrayed as a simplified set of federal requirements, in point of fact the areas that would be covered are very

While the Education of All Handicapped Children's Act of 1975 (P.L. 94-142) is generally credited with having a major impact on assuring youngsters with disabilities access to a free, appropriate public education, the primary effects of the legislation can be traced to provisions mandating state/local practices, rather than the inducement of additional federal aid. Indeed, the law specifies that in FY 1982 and thereafter, the federal government is to cover forty (40) percent of the cost of providing special education services to such children. In reality, however, federal aid to the states under P.L. 94-142 has never exceeded eleven (11) percent of the total cost of special education services to children with handicapping conditions.

broad and would appear to create an opportunity for the promulgation of proscriptive federal standards. The fact that the proposal includes provision for oversight activities akin to federal "look-behind" surveys is equally problematic. While the possibility of permitting states to choose "deemed status" by a third-party accreditation body, as a substitute for the proposed quality assurance mechanisms, is mentioned in the proposal, it seems clear that the intent behind it is to establish a strong federal role in standard setting and program monitoring. This theme does not square well with the objective of giving states greater flexibility. The fact that federal funds would be capped creates an enormous potential liability for the states should the costs of services increase significantly as the result of federal regulatory actions or should the standards themselves prove to be a major source of inefficiency in the delivery of services.

The foregoing considerations represent the major potential problems with the Administration's proposal.

For a variety of reasons, the proposal is schizophrenic, even though, in many ways it is based on a sound appraisal of many of the problems associated with Medicaid financing of MR/DD long-term care services. On the one hand, it is clearly aimed at placing federal outlays for persons with developmental disabilities on a more predictable course, at least from the perspective of the federal government. In addition, there is validity to the proposition that it may not be possible to work out all of the problems currently associated with Medicaid financing of MR/DD services within the context of the Medicaid program. The proposal also gives credence to the notion that decision-making regarding services and programs ought to be decentralized to the state and sub-state level.

On the other hand, in a number of ways the ASPE/HHS proposal would broaden federal involvement in regulating MR/DD services. Yet, taken in conjunction with the proposed funding mechanism, states would be faced with unpredictable fiscal liabilities as a result of expanded federal oversight, coupled with a statutory mandate to serve a broad target population with a fixed amount of federal financial assistance. Additionally, it is unclear how much flexibility the states would have once they extended federally-financed services to the entitled target population. For many states, there is a considerable likelihood that little money would be left over once the minimum service array were furnished to the entitled service population. The net effect would be to leave mildly or moderately disabled adults who have significant ongoing needs for developmental training and support services in the lurch.

Despite the potential problems with the HHS/APSE plan, it is worth keeping in mind that the proposal reveals that there is a substantial level of dissatisfaction with current policies among federal officials. While obviously intended to avoid any further, unpredictable increases in Medicaid spending for persons with developmental disabilities, the proposal also represents a radical departure from conventional efforts to change Title XIX. Despite the exclusion of the HHS/ASPE plan from President Reagan's FY 1990 budget proposals, Departmental officials report that further dialogue on the proposal is expected with incoming representatives of the Bush Administration. Thus, the plan itself, while it may be dormant, it is not necessarily dead.

Core requirements would be defined for: (1) client rights and protections; (2) case management services; (3) the use of federally-specified functional assessment instruments; (4) individual program plans; (5) a "uniform performance accounting system"; (6) "clearly delineated responsibilities of providers serving the individual"; (7) program monitoring; and, (8) minimum health, safety, and sanitation rules.

D. Reforming the Waiver Program

One immediate and direct means of reforming Medicaid would be to correct key problems surrounding the administration and operation of the HCB waiver program. The fact that waiver programs are in operation in 39 states and soon may be initiated in several other states substantiates that the HCB waiver program is an extremely attractive option for states in accessing federal funding on behalf of persons with developmental disabilities. If waiver programs work, then it would appear to make sense to build on an apparently satisfactory approach to furnishing federally-assisted DD long term care services. Recommendations for solidifying the waiver program have ranged from making the HCB waiver authority an optional state plan service to significantly rewriting basic HCB waiver statutes.

In considering this type of strategy, it is useful to point out the basic problems that states have encountered in operating HCB waiver programs. These problems can be summarized as follows:

The cap on the number of persons a state can serve in specialized DD long-term care programs when it opts for a waiver program significantly limits a state's capacity to address current and future unmet needs among the target population for such services. HCFA's administrative policies and practices are focused on keeping utilization/expenditure caps as low as possible and establishing rigorous conditions for a state to meet if it wishes to demonstrate the need for higher utilization and expenditure caps. States that have attempted to gain approval for a higher cap have generally come away from the HCFA negotiation process with less than they originally sought (if anything at all). By and large, the waiver program would be more satisfactory to the states and consumer interest groups if there were a reliable means of assuring a reasonable rate of long-term growth in the number of DD recipients of waiver services as well as the total federal-state cost of serving them.

The second problem is closely linked to the first. As presently administered by HCFA, the waiver program does not permit states to utilize all the savings attributable to reduced utilization of ICF/MR services. In fact, a highly cost effective waiver program yields a reduction in total FFP over time. This problem creates disincentives for states using HCB waiver programs to promote lower-cost, in-home and family support services.

The third major problem has been HCFA's administration of the HCB waiver program. The questionable tactics used to hold down state waiver spending and the general level of federal intrusion into the details of program operations make it difficult for states and other vendor agencies to operate waiver programs.

At least in the short-run, solutions to the problems outlined above would resolve a significant number of issues.

As noted earlier, one proposed solution has been to establish HCB services as a regular state Medicaid plan option. If this step were taken, states would have considerably more latitude to expand home and community-based services and also avoid the highly frustrating periodic renewal process. Indeed, a bill to accomplish this purpose was introduced by Senator Bill Bradley (D-NJ) and Representative Ron Wyden (D-OR) in 1985. The major problem with making home and community-based services a state plan option is that it could have an enormous impact on federal Medicaid spending. Even if the plan option were limited to home and community-based DD services, the potential fiscal impacts would parallel those that might be expected to occur should community habilitation services be authorized as a state plan option, as proposed in Representative Waxman's bill. Unless this option were restricted solely to HCB waivers serving persons with developmental disabilities, the overall impact of this alternative could be very large. It must be kept in mind that the present HCB waiver authority is generic in nature and that many states operate HCB waiver programs

which serve elderly individuals as well as persons with physical handicaps. In addition, even if the HCB waiver program were restructured as an optional state plan coverage, states still would be required to demonstrate that persons receiving such service otherwise would need institutional services; the continuation of this linkage to institutional services would be unsatisfactory for the reasons cited earlier in this report. However, despite the undesirability of continued use of this criterion, it would not necessarily impede states from running up utilization rates in the short run.

It is likely that pursuing a strategy of converting HCB services to an optional state plan service ultimately would entail some type of limitation on the eligibility or the scope of covered services in order to contain the potential fiscal impact of such legislation. One such limitation might involve restricting eligibility for services in some fashion that yields an acceptable rate of growth in federal outlays. In the absence of such a test or some other means of containing the potential dollar impact, the prospects of enacting such legislation would appear to be no better (or worse) than proposals such as Representative Waxman's bill, which can be viewed as essentially an attempt to permit states to convert their HCB waiver programs to state plan status.

It also must be kept in mind that converting the HCB waiver program to an optional state plan coverage would not necessarily solve several key problems that have emerged around HCFA's administration of the program. The Bradley/Wyden legislation, for example, would have maintained the requirement that HCB services be "cost effective" and also continued the practice of having states gain Secretarial approval of proposed waiver programs.¹ While an optional state plan coverage is, in many ways, superior to a "waiver" mechanism, it is by no means certain that many of the problems currently encountered in securing HCFA's approval would disappear under such an arrangement. Indeed, it seems quite possible that HCFA would intensify its scrutiny of state waiver requests.

Another potential solution would be to authorize a new waiver authority along the lines of Section 1915(d) of the Social Security Act, which Congress added in 1987 to give states an additional means of providing home and community-based services to elderly persons. Appendix D contains a description of this authority and analyzes some of its implications for state MR/DD programs. The Section 1915(d) HCB waiver authority, in essence, uses an indexed cap on total long-term care expenditures (institutional and waiver) but permits a state to serve as many individuals as it desires within the limitations of such a spending cap. All savings in institutional expenditures may be recycled to expand home and community-based programs. The fiscal viability of this option depends on: (a) the index rate used; and, (b) the extent to which a state actually believes that institutional cost savings can be achieved. However, there is no doubt that the Section 1915(d) formula is vastly superior to the one presently employed by HCFA to regulate spending and participation in HCB waiver programs serving persons with developmental disabilities. While an earlier draft of Representative Waxman's H.R. 5233 contained provisions which would have extended the Section 1915(d) option to MR/DD HCB waiver services (including providing for a minimum indexed rate of growth in federal payments of 11.5 percent), the bill as introduced did not include those provisions.

While provisions similar to Section 1915(d) would, in essence, be budget neutral and, hence, should raise few objections from a federal budgetary perspective and might be legislatively viable, the issue of HCFA's administrative policies and practices remains. Under the terms of Section 1915(d), the provision of home and community-based services to persons with developmental disabilities would still require Secretarial approval of a state's waiver request as well as periodic renewals of such requests. The major change is that "cost effectiveness," as currently regulated by HCFA, would become moot. Thus, while major problem areas for the states - the cap on the number of persons who may receive HCB waiver services and the difficulties in reprogramming institutional cost savings — would be removed through the creation of an authority similar to Section 1915(d), many of **the** problems associated with HCFA's administrative policies and practices would still remain under a Section 1915(d)-like waiver authority.

While statutory provisions authorizing waiver services can be amended to address at least some of the problems raised by HCFA's administrative policies and practices (indeed, this has occurred on numerous occasions in the past as a reaction to federal actions that were viewed as particularly threatening to the states), it must be recognized that so long as the approval of a waiver remains a matter of Secretarial discretion, a hostile administration can create interminable roadblocks to accessing federal funds. Thus, a "waiver reform" strategy can be developed that addresses some but not all of the problems states may experience in dealing with HCFA.

One must also recognize that a reform strategy focussing solely on the HCB waiver program would leave unresolved many of the other key issues regarding Medicaid policies. In a waiver context, for example, the "need for institutionalization" probably would remain a key test of eligibility. In addition, current problems surrounding the ICF/MR program would not be directly affected by such a strategy. Perhaps most seriously, focusing on waiver reform requires states to accept a cap on federal Title XIX assistance. Some states are in a better position than others to accept such a cap. However, consumer and provider interest groups can be expected to react negatively to any strategy that focuses on the HCB waiver program as a vehicle for Medicaid reform; they will argue that waiver reform might be regarded by Congress as a panacea for all problems and, hence, blunt efforts by such groups to achieve a broader base of support for Medicaid funding of community-based services on behalf of persons with severe disabilities.

In previous years, New York State has proposed an approach roughly similar to the financing features of the Section 1915(d) waiver authority but has been unable to enlist sufficient support to have a bill to accomplish these ends introduced in Congress. [N.B, More recently, New York has received HCFA's support for a two-year, demonstration project aimed at defining how this type of approach might be employed on a limited basis in the state.]

It is important to point out, however, that two key ingredients in New York's proposals have been to: (a) allow the states greater flexibility in defining Medicaid reimbursable services; and (b) secure some measure of regulatory relief from ICF/MR standards. Congressional discussions regarding the possibility of an authority similar to Section 1915(d) for persons with developmental disabilities have not contemplated the degree of flexibility that New York officials view as essential to the acceptance by a state of a limitation on the rate at which Medicaid spending expands.

E. Incrementalism

Some may argue that the only sensible Medicaid reform strategy — particularly given the difficulty in securing adoption of measures aimed at program expansion in the context of the current, hostile budgetary environment — is to pursue limited, incremental changes. Clearly, the experience of the past seven-eight years suggests that this approach may be the least satisfying, but the most pragmatic method of changing Medicaid policies. The incrementalist approach is based on proposing only limited changes that will set the stage for additional follow-up actions; under this approach, federal policies change, but the process occurs over an extended period of time. The authority to claim Medicaid reimbursement for supported employment service on behalf of waiver recipients provides a practical illustration of this approach. In 1986, such services were extended to former institutional residents who were participating in HCB waiver programs. Next year, Congress may permit such services to be made available to all HCB waiver recipients. [N.B, Such a provision is included in Mr. Waxman's bill (H.R. 5233).]

While incrementalism may fit the tenor of the times better than proposing a sweeping restructuring of Medicaid policies as they affect persons with developmental disabilities, incrementalism will not yield satisfactory solutions to a number of major problems associated with Medicaid policies in the near-term. In addition, some issues are so overarching that an incrementalist approach is simply infeasible. One example lies in federal regulation of ICF/MR services. Short of a significant reconceptualization of the ICF/MR program, it is difficult to conceive of an incrementalist strategy that would reduce the current pressure to enhance ICF/MR services and thus raise state and federal program costs.

While incrementalism can be employed to achieve targeted change in federal policies, it has its limits. At the same time, it is important to recognize the necessity of continuing to pursue incremental changes as a means of mitigating some of the near-term negative consequences of existing federal policies.

F. Summary

While the Chafee/Florio legislation obviously represents the most widely recognized effort to secure sweeping reforms in existing federal Medicaid policies affecting persons with developmental disabilities, other strategies have emerged or are being developed. Each of these various strategies have desirable features, but none offers totally satisfactory solutions to all the perceived limitations of current federal Medicaid policies as their impact on persons with developmental disabilities. It seems clear that the potential success or failure of any strategy is inextricably tied to the federal deficit problem. Budget neutral proposals or proposals having relatively minor budgetary impacts are more likely to be enacted than proposals that would increase federal spending significantly. Proposals with limited budgetary impacts, however, involve trade-offs in the areas of service coverage and eligibility standards that may prove unacceptable to key constituencies in the field of developmental disabilities. This is the underlying dilemma facing all parties interested in restructuring existing Medicaid policies.

While the legislative consequences of the recently heightened interest in reforming federal Medicaid policies are unclear at present, it is important to note that the interest of both Congress and some federal officials have been engaged. Thus, there are at least indications that the stage has been set for legislative action of some type.

CHAPTER V

CRITICAL MEDICAID REFORM ISSUES

V. CRITICAL MEDICAID REFORM ISSUES

In the preceding chapters of this report, we have described the growing influence of Medicaid financing on the organization and delivery of specialized long term care services to persons with developmental disabilities. At the same time, we have pointed out several fundamental changes in the philosophical constructs that undergird the provision of such services, as well as the ways in which these seminal shifts in program philosophy have led to increasing pressure for basic changes in federal Medicaid policies affecting the delivery of long term care services to persons with developmental disabilities.

Now that we have reviewed the principal provisions of existing proposals to restructure applicable federal laws (see Chapter IV), it is important to identify the most critical dimensions of federal Medicaid policies that need to be addressed in formulating a holistic legislative proposal. It also is important to understand the difficult choices faced by the architects of such proposals as they attempt to balance their reform objectives with the realities of the political process. The purpose of this chapter, therefore, is to pinpoint the most significant challenges to designing a piece of Medicaid reform legislation that is both politically feasible and capable of resolving the principal inequities of existing policy.

A. Eligibility For Medicaid Services

The area of eligibility constitutes one of the most complex, yet critical aspects of Medicaid policies affecting persons with developmental disabilities. Widening or narrowing the target population of persons eligible to receive Medicaid-financed services can be expected to have a substantial impact on not only the costs of delivering services, but also on the political feasibility of proposed legislation. Yet, if the parameters of eligibility are defined too strictly, one of the principal goals of reform legislation -- i.e., to make appropriate habilitation and support services available on a more equitable basis to disabled Americans who require such services — could be seriously undermined.

1. Current Policies

Present federal and state policies governing eligibility determine the extent to which persons with developmental disabilities may access the services a state makes available to all Medicaid recipients as well as the specialized developmental disabilities services authorized under the state's Title XIX plan. The degree of access, coupled with the types of services a state chooses to furnish under its state plan, determine the relative role the Medicaid program plays in meeting the costs of state-supported services to persons with developmental disabilities.

Under current Title XIX law, a state offering Medicaid-reimbursable long-term care services to persons with developmental disabilities (via either the ICF/MR or the HCB waiver program) must structure its eligibility policies under the umbrella of the following three federally-defined parameters:

Disability. In order to be eligible for ICF/MR or HCB waiver services, an individual must be either mentally retarded or have a condition closely related to mental retardation.

Need for Institutionalization. It must be demonstrated that a person needs the regimen of services furnished in an ICF/MR-certified facility (i.e., the provision of "continuous", "aggressive" active treatment services, coupled with constant oversight and supervision). This test applies to recipients of ICF/MR services as well as participants in community-based services financed through

a Medicaid HCB waiver (although the "active treatment" standard per se is not applicable to waiver programs).

Income. An individual must meet the income/resource tests adopted by a state to regulate which low-income persons are allowed to use Medicaid-assisted acute and chronic care services.

As discussed in Chapter II, a state may tailor its eligibility criteria governing Medicaid-reimbursable long-term services to meet a variety of objectives. Current Medicaid law grants states numerous (but highly complex) choices concerning the type of persons who are treated as eligible to receive Medicaid-reimbursable long term care services, as long as state policies comport with basic federal statutory and regulatory requirements.

2. Unresolved Issues

In this area of policy, as in the area of service coverages (see below), existing laws create problems due to the so-called "institutional bias" of the Medicaid program. Access to specialized services is regulated by the "need for institutionalization" test, a determination that is out-of-step with key values which undergird contemporary DD service delivery practices. Consequently, debate centers on potential substitutes for (or complements to) this eligibility test. For a host of reasons, the institutional needs test has restricted participation in Medicaid-reimbursable DD long-term care services to approximately 175,000 persons out of an estimated 1.1 million individuals who are developmentally disabled and meet other federal tests regarding the severity of their handicapping conditions. This extremely large gap between the actual and potential number of Medicaid recipients with developmental disabilities means that changing this test could have an enormous impact on both state and federal Medicaid expenditures.

States increasingly are reluctant to undertake any broad-based expansion of ICF/MR services due to the high cost of such services as well as the field's increasing reservations about the appropriateness of ICF/MR services for the large majority of persons with developmental disabilities. At present, only the HCB waiver program offers a state the opportunity to employ Medicaid dollars to finance more cost-effective services that are better synchronized with contemporary views regarding the most appropriate service modalities. Present HCFA administrative policies, however, cap participation in such programs according to a state's current and projected ICF/MR bed capacity. With three-quarters of the states operating HCB waiver programs, closing the gap between actual and potential beneficiaries is effectively stymied. Most observers believe that a substitute for, or complement to, the "need for institutionalization" test is needed to allow the states to enhance the rate of participation in Medicaid-reimbursable DD long-term care services.

Other issues in this area include: (a) the degree to which all states should be required to extend eligibility to a minimum target population of individuals with developmental disabilities and, hence, create a minimum floor of access to services, nationwide; (b) the extent to which persons who do not meet the current disability test but have severe handicapping conditions should be eligible to receive Medicaid-reimbursable services; and, (c) the most appropriate methods of promoting equal access to Medicaid-funded long-term care services, regardless of a person's living arrangement, in order to counter the oft-cited criticism of federal Medicaid law that existing eligibility criteria create incentives to serve persons in institutional settings rather than in their own homes.

With respect to the definition of the eligible target population, the primary Medicaid reform issue is whether federal policies ought to be changed to require all states to cover a uniform service population and, if so, how that service population ought to be delineated. Should, for example, federal law authorize coverage - either on a mandatory or optional basis - for populations other than persons with

developmental disabilities (e.g., individuals with traumatic brain injuries or chronic mental illness)?

Furthermore, while Section 1619(a) and (b) of the Act removes the employment disincentive inherent in previous policies, an employed individual with chronic disabilities still loses Medicaid and SSI benefits once his or her earnings reach defined thresholds. Despite the significant advantages afforded by the 1986 legislation, the linkage between SSI and Medicaid eligibility still poses a conflict between obtaining and retaining federal cash assistance on the one hand and achieving economic self-sufficiency through employment on the other.

3. Proposed Solutions

The possible approaches to revising the federal basis of eligibility for specialized Medicaid-reimbursable long-term care services might be summarized as follows:

- a. For non-institutional community-based services, remove the "need for institutionalization" test and place access to such services for persons with severe handicaps on an equal footing with eligibility for institutional services. This approach was adopted in drafting the Chafee/Florio bill. In lieu of the "need for institutionalization" test, eligibility for family and community-based support services authorized under this bill would be based on whether a person qualifies as severely handicapped under current SSI disability criteria. Such criteria would displace both Medicaid's existing disability test as well as the "need for institutionalization" test as the standard for determining whether a person qualifies for the federally-reimbursable non-institutional services specified in the legislation. A practical outgrowth of the Chafee/Florio legislation is that all states would be required to adopt this eligibility standard for both the legislation's mandatory service array as well as any of the twenty other optional services a state may elect to cover. In addition, by gradually increasing the age of onset of disability, eligibility for such services would be expanded to include a larger population of persons with severe disabilities who do not fit the current federal definition of developmental disabilities.

With regard to income and resources, the Chafee/Florio bill would mandate that states apply exactly the same test of federal eligibility for community-based services as is applied for institutional services. In addition, states would be granted the discrete option of covering children with severe disabilities who are living at home, by waiving the deeming of parental income and resources.

Advantages. Tying coverage of Medicaid-reimbursable services to the existing SSI disability criteria would give persons with severe handicaps much broader access to family and community support services. Eligible persons would include those who are generally regarded as needing long-term services and supports (i.e., persons whose degree of disability indicates the need for life-long "supportive services and assistance due to impairments that make self-support unlikely). Decoupling eligibility for family and community services from the "need for institutionalization" would allow states to increase the number of persons who receive Medicaid-reimbursable benefits, by breaking the tie between receipt of such services and the individual's need for a facility-based program. There is little doubt that linking eligibility to the need for increasingly expensive ICF/MR services has resulted in a relatively small percentage of individuals who might benefit from the provision of community-based services

actually participating in Medicaid supported DD long-term care services. By detaching eligibility from the individual's need for a particular type of specialized service (i.e., admission to an ICF/MR), the legislation would permit the provision of services to be better tailored to the person's circumstances and needs. For ICF/MR services, current policies would remain in place and, hence, this change would not affect the eligibility of current or potential residents of such facilities.

Decoupling eligibility from the "need for institutionalization" test also would negate the most critical shortcoming of the HCB waiver program — i.e., the stringent federal restrictions on the number of program participants, which are an outgrowth of the Administration's goal of restraining waiver spending. In addition, many observers would argue that the principal national aim in this area of policy should be to assure that at least a "core" group of similarly situated individuals have access to essential services, regardless of the state in which they live. The Chafee/Florio bill would represent a major step toward achieving that goal, since all states would be required to furnish the mandated array of community and family support services to recipients with developmental disabilities, initially and, eventually to a much wider population of non-elderly persons with severe chronic disabilities.

Access to family and community-support services also would be enhanced by the requirement that the same financial criteria be used in determining eligibility for institutional and community-based services. A state would continue to have the choice of extending eligibility to other groups, by selecting additional Medicaid financial eligibility options. The legislation also would permit a state to target family and community support services to children living at home, hence providing a state with greater flexibility in meeting the needs of such persons (and, potentially, reducing the demand for more expensive modalities of long term care services).

Finally, the proposed expansion of eligibility beyond the traditional developmental disabilities population may be a means of addressing other defects in federal policies that substantially limit access to appropriate support services by persons who become mentally or physically impaired later in life.

Disadvantages. Extending eligibility to all persons who meet the disability criteria - along with the Chafee/Florio bill's mandate that such individuals be entitled to receive a core set of services ~ could have enormous fiscal consequences for both the states and the federal government. This change would substantially increase participation in specialized Medicaid-reimbursable services by mandating that states close the gap between the current number of program participants and the number of persons potentially eligible for Title XIX reimbursable services. To some degree, this gap would be closed merely by qualifying for Medicaid reimbursement

existing DD community services that are currently financed with state dollars. Most states, however, would face the prospect of substantially increasing the overall scope of the services they presently furnish to persons with severe disabilities. Consequently, both federal and state spending could be expected to rise dramatically.

While states at present can regulate program participation (particularly under the HCB waiver program) and, thus, program expenditures, doing so under the Chafee/Florio bill would be more difficult, given the legislation's mandatory eligibility provisions and the minimum service array. Hence, the legislation could pose a substantial threat of budgetary stability in many states. Problems similar to those states have encountered in regulating Medicaid expenditures for acute care health services could arise in state MR/DD programs.

Finally, authorizing family and community-based services for individuals who presently are not eligible to receive services furnished by state MR/DD agencies could have far-reaching consequences for the overall scope and range of services furnished in most states. The fiscal consequences of this change are impossible to estimate, but there is little doubt that the potential cost would be enormous.

- b. Retain the traditional approach of targeting Medicaid reimbursable services to persons a state finds eligible for optional Medicaid benefits. Basically, this is the approach proposed by Representative Waxman in H.R.5233. Mr. Waxman's bill retains the conventional, mainstream approach to expanding Medicaid eligibility — i.e., it would allow states the latitude to define specific eligibility criteria under the general umbrella of Medicaid law. This latitude would roughly parallel the authority enjoyed by the states under current law. Persons receiving public assistance (i.e., SSI or AFDC benefits) would have to be covered (as in the case of any optional state plan service) should the state elect to furnish community habilitation services. States could broaden coverage — at their option — to other income groups. If a state chose to do so, however, the "need for institutionalization" test would apply to this optional group of recipients.

In addition, the legislation maintains the focus of Medicaid-reimbursed services on the target population presently eligible for such services - i.e., persons with mental retardation or "other related conditions." The Waxman bill, however, would empower the Secretary to establish a new uniform federal test of the "need for institutionalization", by requiring that criteria governing the appropriateness of ICF/MR services be developed by HCFA.

Advantages. The chief advantage of the Waxman approach is that it maintains a state's discretion to decide the types of persons it consider to be eligible to receive Medicaid-reimbursable services. States would be authorized to operate in the controlled eligibility environment of the HCB waiver program or to select the community habilitation services option. Under the latter option, states could choose to regulate eligibility based on state statutory criteria and, furthermore, limit, at their discretion, eligibility based on specified income tests. As a consequence, compared to the Chafee/Florio bill, states

would be better able to control the potential fiscal impact of the use of Medicaid financing in their community service delivery systems.

The Waxman legislation is distinguishable from the Chafee/Florio bill in another eligibility-related way. Under the Waxman bill, a state would have significant latitude in defining the range of community habilitation services and, consequently, be in a stronger position to regulate program participation and, thus, expenditures.

Disadvantages. The principal disadvantage of this approach is that it would continue the use of the "need for institutionalization" test of eligibility, at least for potentially eligible recipients who are not entitled to SSI benefits. The differential imposition of this test could result in service delivery system schizophrenia. Persons, who by virtue of their disability and general economic circumstances (particularly in the case of OASDI recipients) are similar to SSI/AFDC recipients, would be required to meet a secondary (and generally inappropriate) test of eligibility in order to receive services. As a consequence, promoting equal access to services would be difficult.

The problems associated with this schizophrenia could be accentuated by the provision of the bill authorizing the Secretary to develop preadmission screening and annual assessment criteria governing eligibility for ICF/MR services. If HCFA were to define such criteria narrowly, many current ICF/MR residents could be adversely affected. In addition, eligibility for community-based services -- either under a state's HCB waiver program or under the proposed community habilitation services option -- would be affected (probably adversely).

The legislation's affirmation of state discretion in determining the parameters of eligibility can be viewed as a disadvantage. In many states, eligibility parameters are determined, not by DD system managers, but rather on a more global level, based often on concerns about the rate of overall growth in Medicaid spending. As a consequence, decisions regarding the access of persons with developmental disabilities to Medicaid-reimbursable services may become immersed in general program eligibility restrictions, as part of an across-the-board effort to contain Title XIX outlays. Restricting eligibility for services represents one of the principal devices available to a state that is seeking to restrain Medicaid expenditures. Experience indicates that, when services are available on an optional basis and states exercise relatively greater control over the number and types of persons receiving such services, the eligibility of persons with developmental disabilities for Medicaid-reimbursable services can be affected negatively by general state actions to limit Title XIX outlays.

Retain current eligibility policies but relax existing provisions governing the number of individuals who may be served in HCB waiver programs. In 1987, Congress established a new waiver authority for elderly persons

under Section 1915(d) of the Social Security Act. This new authority permits a state to expand the number of persons receiving HCB waiver services beyond the levels HCFA might otherwise authorize under its present "cold bed" policy (see discussion of this issue in Chapter IV and Appendix D). If a similar authority were added for DD waiver services, states would have the option of expanding participation in HCB waiver programs whenever institutional spending reductions were not fully offset by increases in community-based waiver spending. Alternatively, some observers have suggested that present HCFA policies governing the evaluation of the "cost effectiveness" of HCB waiver programs could be changed, statutorily, to provide a different basis for determining the maximum number of persons who may receive such services. For example, proposals advanced by New York State have been based on "indexing" the rate of growth in federal reimbursement and program participation.

Advantages. The ability of states to regulate program participation rates makes the HCB waiver program an attractive means of managing the overall scope of Medicaid funding for community-based DD services. Under a waiver, in essence, a state may determine the precise number of persons who will receive Medicaid-reimbursable services out of the entire pool of potentially eligible recipients. Consequently, the waiver program promotes state budgetary stability, thereby making it easier for DD managers to "sell the merits of expanding Medicaid-financed community services to elected and supported state policymakers. At the same time, HCFA's stringent limits on the number of individuals who may be served in waiver programs substantially reduces the attractiveness of this financing option. Under present federal waiver policies, states are unable to expand Medicaid-financed community services beyond a certain point (generally defined as the number of current and potential new ICF/MR beds that would be "decommissioned" as a result of the proposed waiver program).

If a statutory authority similar to Section 1915(d) were established for persons with developmental disabilities), or a more liberal basis was used in determining the maximum number of persons to whom a given state could provide HCB waiver services (e.g., defining a growth allowance other than "cold beds"), the utility of the waiver program would be greatly enhanced for many states. Waiver services could be expanded while at the same time allowing a state to retain its capacity to regulate program expenditures. In addition, from a federal budgetary perspective, waiver-based strategies yield more predictable estimates of the potential fiscal impacts.

Disadvantages. The disadvantages of a waiver-based strategy in this area might be summarized as follows:

HCFA Policies. HCFA policies governing the use of the HCB waiver authority have been predicated on a policy of restricting the fiscal impact of waiver services. Employing the waiver as a vehicle to expand access to community-based services would be difficult without simultaneously addressing all of the problems associated with HCFA's current administration of the program.

Thus, under a Section 1915(d)-like option, states could find themselves in the position of having greater flexibility to increase the number of waiver participants, only to find that HCFA imposes new administrative barriers to such expanded coverage.

Interstate Variations. Efforts to use waiver-based strategies to increase the number of persons receiving Medicaid-reimbursable community-based services will have an uneven impact from state to state due to the significant degree of variation in the states' utilization of Medicaid-funded DD long-term care services. Unless fairly complex formulae are employed, broadening participation — either through the Section 1915(d) approach or by requiring HCFA to apply more liberal parameters in regulating the growth of Medicaid-reimbursable long-term care services — could benefit only a limited number of states (mainly those states, which historically, have made extensive use of Medicaid financing for DD long-term care services).

Inappropriate Test. Finally, eligibility for HCB waiver services is explicitly linked to a demonstration of the individual's "need for institutionalization." A waiver-based strategy obviously would involve a continuation of this test, even though it is viewed as unsatisfactory by most professionals and consumers in the field of developmental disabilities. In addition, states would remain vulnerable to Congressional (e.g., the Waxman bill) or Administration initiatives to narrow the number of persons eligible for ICF/MR services.

Thus, while the HCB waiver program permits states to regulate program participation (and, hence, eligibility), it is not clear that a waiver-based strategy could serve as more than a temporary means of resolving the eligibility issues outlined above.

4. Summary

Each of the various proposed solutions to the **unresolved** issues in the area of eligibility policy would significantly affect who might have access to Medicaid-reimbursable services. The fact that present policies **have resulted** in only a distinct minority of Americans with developmental disabilities participating in services makes it extremely difficult to identify solutions that **at once acknowledge** the broad-based need for services while not triggering potential increases **in** utilization that would render new legislation infeasible due to high potential **fiscal** impact.

B. Medicaid Coverage of Community Services

Coverage of services (e.g., the range of services **that are eligible for** federal Medicaid financial participation) represents a second, thorny **area of policy debate**. The question of "eligible for what?" is equally as important as the question of who **will** be deemed to have access to Medicaid -reimbursable services.

1. Current Policy

As a basic condition of participating in the Medicaid program, a state must offer certain types of services (generally referred to as mandatory coverages), including inpatient and outpatient acute hospital services, physicians services, laboratory and x-ray services, skilled nursing facility services, home health services for persons over 21 years of age, early periodic screening, and certain other services. In addition to these mandatory coverages, a state may elect to cover certain optional services.

Under existing Medicaid law, states may not claim Title XIX reimbursement for long term care services provided to elderly and disabled persons in non-institutional settings unless such services are furnished either: (a) as part of a HCB waiver program approved by the Secretary of Health and Human Services; or (b) under one of several existing state plan options (e.g., personal care; home health services; clinic services; and medical rehabilitation and other remedial services) that a state may elect to cover under its Medicaid plan.

Generally, if a state chooses to offer any of the optional service coverages that are currently recognized under federal law and regulations, it must provide the Secretary with assurances that such services will be made available on a statewide and comparable basis. In other words, the subject category of services must be geographically accessible to all residents of the state and be made available to all similarly-situated Medicaid recipients who need such assistance.

2. Unresolved Issues

The most critical shortcoming of current Medicaid policy, as it impacts on persons with developmental disabilities, is the lack of a reliable basis for claiming Title XIX reimbursement for long term care services in non-institutional settings. There are numerous ramifications of this so-called "institutional bias" of Medicaid policy (e.g., eligibility; regulating and monitoring the quality of community services; etc.) that will be discussed elsewhere in this chapter; but, as far as the actual scope and extent of the services covered, the key questions are: (a) what additional elements of services should be made eligible for Medicaid reimbursement; and (b) how broadly or narrowly should such non-institutional services be defined? The answers to these questions involve difficult trade-offs between an expansion in the number of eligible recipients and the related impacts on federal and state Medicaid budgets.

Other issues that must be weighed include: (a) whether any proposed new services should be mandatory or optional state plan coverages; and (b) whether such services should be subject to the existing statutory requirements that state plan services be furnished on a statewide and comparable basis.

3. Proposed Solutions

The possible approaches to securing a more reliable basis of Medicaid support for community-based services might be summarized as follows:

- a. Seek Medicaid coverage of a broad array of services and supports that play a critical role in assisting persons with developmental disabilities to live successfully in home and community-based settings. This, in essence, was the approach used in drafting the Chafee/Florio bill. The umbrella

Targeted case management services, as authorized under Section 1915(g) of the Act, is an exception to this rule. A state, by law, may restrict the availability of case management services to particular target population and/or to specified geographic areas of the state. Similarly, an HCB waiver program also is targeted.

term "community and family support services" is defined to encompass some 24 elements of services and supports that are viewed as essential to assisting persons with severe disabilities to live at home or in other community-based residential environments. Within two fiscal years of enactment of the legislation, states would be required to cover at least four, specified elements of community and family support services (case management; individual and family support services; specialized vocational services; and protective intervention services); in addition, states would have the option of covering any of 20 other elements of CFS services enumerated in the legislation.

Advantages. The ability to cover an extensive array of Medicaid reimbursable services and supports should provide the states with relatively greater latitude in responding to the needs of persons with developmental disabilities. Such flexibility would be particularly advantageous in instances where non-habilitative services and supports (e.g., respite care; family support; attendant care; etc.) were seen as the most effective and economical approach to maintaining individuals at home or in alternative community-based settings. In addition, greater statutory specificity in defining the elements of coverable services should limit the possibility of federal regulatory and administrative interpretations to restrict the types of service/support costs that a state may claim for purposes of Title XIX reimbursement.

Disadvantages. Broadly defined coverages are likely to result in higher federal-state Medicaid costs which, in turn, would make it more difficult to enact reform legislation. While it may not be possible to identify the point on the political fulcrum at which a proposed expansion in service coverage becomes no longer viable, it seems clear, given the current federal budget deficit, that Congress' tolerance for growth in Medicaid outlays associated with any new coverage option is likely to be quite limited. One might reasonably predict, therefore, that the prospects of enacting substantial changes in Medicaid policy would plummet if one were to insist on breaching such political tolerance levels.

Furthermore, it can be argued that an extensive "laundry list" of coverable Medicaid services may raise expectations that most states simply would be unable to fulfill in the foreseeable future. Given the pressures the states are under already in their efforts to serve the traditional DD population, it seems doubtful that many states would elect service options that would qualify entirely new populations for Medicaid-reimbursable services and supports. The benefits that might be realized by consumers in a small handful of states then must be balanced against the fiscal and psychological consequences of a proposal to add an extensive array of new, potentially costly coverages.

Finally, the general problems associated with legislating a comprehensive array of new home and community-based coverages would be complicated even further by mandating that the states cover certain of those services. The history of the Medicaid program, since its inception, has been that each state exercises considerable latitude in

defining the scope and composition of its own program. As a result, Congress generally has elected to expand the range of reimbursable services by adding new optional coverages, rather than mandating the provision of services. Given this history, it is likely that there will be considerable opposition within Congress and the states to new service mandates, particularly since such requirements would be perceived as placing further budgetary pressures on an already rapidly growing program.

- b. Support Medicaid state plan coverage of certain core community-based services only. The Waxman bill (H.R. 5233) exemplifies this approach. It would authorize the states to offer "community habilitation services" as an optional coverage under their Medicaid plans, effective October 1, 1989. In order to cover such services, however, a state would be obligated to provide assurances satisfactory to the Secretary that certain "fair and equitable arrangements" would be made to protect the interests of employees who might be impacted by the provision of such Medicaid-funded services. In addition, under H.R. 5233, providers of community-based residential habilitation services would be required to meet federally prescribed standards in order to qualify for Medicaid reimbursement.

The implications of these prerequisites to covering community habilitation services, as contained in the Waxman bill, are dealt with in separate sections of this chapter. Here we will address only the basic ramifications of adding a limited purpose optional service coverage under Medicaid.

Advantages. To the extent that it is feasible at all to convince Congress to add new community-based service coverages, the possibilities of doing so should be significantly enhanced by limiting the focus (and, consequently, the potential fiscal impact) of such newly authorized services. The prospects of enacting such legislation also should be significantly improved if the proposed new coverage is presented as an additional state plan option, rather than as a mandatory service coverage (as suggested in the Chafee/Florio bill).

Assuming that the types of reimbursable services are carefully selected and defined in the legislation, it should be possible to minimize the disadvantages of a more narrowly focussed coverage of community-based services. Based on the states' experiences with Medicaid home and community-based waivers, it seems apparent that the vast majority of costs a state is able to claim under a waiver program could be claimed under the Waxman definition of "community habilitation services" - and, more importantly, with less direct federal control over the number and types of persons found eligible by a state to receive such services.

Disadvantages. As the provisions of the Waxman bill suggest, the political "price" of obtaining authority to cover community-based services under a state's regular

Practices in classifying service costs for purposes of waiver reimbursement vary markedly from state to state. Habilitation services, however, is usually the principal billing code used by most states; indeed, in some states it is practically the only basis for claiming Medicaid reimbursement under MR/DD waiver programs.

Medicaid plan may be a variety of new requirements (e.g., federal operating standards; and far reaching new employee protections) that many states will view as particularly onerous. If, as a result, most states choose not to cover such services under their Medicaid plans - opting instead to continue to operate programs under the HCB waiver authority, despite its pitfalls ~ the principal aim of the legislation will not be accomplished.

Even if most states eventually would elect to offer "community habilitation services" as an optional state plan coverage (either with or without modifications in the Waxman conditions), some Medicaid induced distortions in policies governing state-supported community services may persist. For example, it could be argued that a state plan service that emphasizes skill training, as opposed to the provision of necessary supports, would lead the states to stress the delivery of clinically-oriented services furnished in congregate settings (e.g., group homes, work activity centers, etc.), even when supportive assistance to the individual or his/her family may constitute a more appropriate, satisfactory and economical approach to meeting the individual's needs.

If one believes that the next frontier in public programming for persons with developmental disabilities is to enable most such individuals, with the assistance of family members and other "natural support structures", to carve their own niche in the social fabric of the community — as opposed to continuing to reside in specialized living facilities and attend segregated training programs — then greater emphasis will have to be given in the legislation to allowing states to organize and deliver family assistance services, attendant services, and other types of individual supports that are necessary to maintain such persons in truly integrated community settings. Restricting Medicaid reimbursement to services with a clear habilitative goal would hamper efforts by the states to adapt to such new realities.

Authorize home and community-based services as a Medicaid state plan option, on either an across-the-board or limited access basis. The principal limitations of the existing Medicaid home and community-based waiver program can be summarized as follows:

The manner in which HCFA limits the number of participants in HCB waiver programs (i.e., restricting the number of participants to a state's actual and planned ICF/MR bed capacity) makes it extremely difficult for most states to address the needs of unserved and underserved members of the target population. As suggested earlier in this chapter, the waiver program would be a more acceptable long-range method of financing home and community-based DD services if there were a reasonable and predictable means of recognizing the growing demand for long term care services in non-institutional settings. Basing waiver utilization limits on a state's current and projected ICF/MR bed capacity clearly represents an unfair and

inequitable method of delimiting the scope of a state's waiver program.

A closely related problem with the HCB waiver program is that, under current HCFA policies, states are not permitted to use all of the savings associated with reduced reliance on ICF/MR services to further expand participation in Medicaid-financed home and community-based programs. In fact, a state with a highly cost effective waiver program (Le., one where the average per capita cost of waiver services is considerably below the average per capita ICF/MR cost) will realize a net reduction in federal financial participation in Medicaid-funded MR/DD services over time (i.e., compared to what it would have received in the absence of the waiver program). Consequently, states have little incentive to promote lower cost service options, such as in-home training and family support services, through their waiver programs.

The degree of federal intervention in the day-to-day management of HCB waiver programs makes it difficult for states, as well as local vendor agencies, to plan, develop and operate waiver-funded services. The ground rules keep changing and, as a result, states and other provider agencies have to devote an inordinate amount of time and energy to satisfying federal administrative requirements that have little to do with the quality and appropriateness of the services furnished to program participants.

One approach to resolving at least some of the problems outlined above would be to permit states to cover home and community-based services under a regular Medicaid state plan option. Indeed, such a proposal was advanced by Senator Bill Bradley (D-NJ) and Representative Ron Wyden (D-OR) in 1985. A less far-reaching variant of the Bradley/Wyden approach would be to allow states that successfully operated HCB waiver program for a given number of years (e.g. six years) to subsequently offer such services as an optional state plan coverage.

Advantages. This approach would give the states considerably more latitude to expand home and community-based services, since HCFA's existing regulatory limits on participation in such services presumably would no longer apply. Thus, even if the cost neutrality rule were maintained as part of the state plan option, the states would not have to use HCFA's methodology for determining utilization and expenditure caps. In addition, states would be able to avoid many of the frustrations associated with HCFA's micro-management of the HCB waiver program, especially the disruptions and uncertainties of having to renegotiate a waiver agreement with HCFA once every 3 to 5 years.

Assuming for the moment that Congress was unwilling, due to fiscal uncertainties and conflicting points of view expressed by various interest groups, to authorize a full-fledged state plan option, the notion of offering this option only to states that had successfully operated a HCB waiver program for a given number of years might prove to be an

acceptable alternative. It could be argued, for example, that states with a proven track record in operating HCB services, at some point should be allowed to integrate such services into their ongoing Medicaid state plan coverages. Furthermore, the near term federal cost impact of this approach should be somewhat easier to predict, since the experiences and future plans of the affected states could be examined before they received Secretarial approval of their HCB state plan amendment.

Disadvantages. First, if the existing home and community-based waiver authority were converted to a state plan option (as proposed in the Bradley/Wyden bill), this new plan option would apply to home and community-based services for frail elderly and other disabled persons as well as persons with developmental disabilities. While, based on experience with the HCB waiver program to date, a case can be made that access to waiver services has contributed to a real reduction in the states' ICF/MR bed capacities, elderly/disabled waivers have not (and, given the demographic realities, cannot be expected to have) the same impact.

Consequently, across-the-board coverage of all long term care populations under a HCB state plan option would result in a substantial risk of multi-billion dollar increases in Medicaid outlays during future years, particularly in view of the anticipated growth in the number of frail elderly persons over the next three decades. Yet, in practical political terms, it is likely to be extremely difficult to authorize a HCB state plan coverage for persons with developmental disabilities and not do the same for other long-term care populations (especially elderly Medicaid recipients).

Second, even if a separate state plan coverage for the MR/DD population could be justified, it is not clear that it would be possible to enact such legislation given the unpredictable impact it would have on federal Medicaid outlays. The problems in this respect would be similar to those already discussed in the case of the Chafee/Florio bill and, to a lesser extent, the Waxman bill.

Third, the states have no assurance that Congress would not attach unpalatable conditions to the coverage of HCB services under a state's Medicaid plan. Indeed, if the Waxman bill is any guide, the likelihood is strong that there would be significant "strings" associated with any new state plan coverage of this type - some of which may lead states to conclude that the risks of such coverage outweigh the benefits.

Finally, one must keep in mind that, if the existing HCB waiver program simply were converted to a state plan option, some of the current problems associated with waiver management also could be expected to be carried forward. For example, presumably eligibility for HCB services still would be tied to an individual's need for institutional services, even though this test, in many ways, works at cross purposes with the states' fundamental

community service goals. Similarly, states still would be obligated to demonstrate that HCB services are "cost effective". Even though HCFA would not be able to exercise such highly detailed control over the operation of HCB services as it does under the waiver program, it could (and probably would) issue prescriptive regulations/guidelines and monitor the states' compliance with such rules/policies very closely. The ultimate weapons at HCFA's disposal, of course, would be the authority to approve or disapprove a state's request to cover HCB services under its state Medicaid plan, and to withdraw such authority at any time agency officials might conclude that the state was failing to comply with applicable coverage requirements.

- d. Authorize an additional HCB waiver authority for persons with developmental disabilities that parallels the language of Section 1915 (d) of the Act. As discussed in Chapter IV, in 1987 Congress added a new waiver authority under Section 1915(d) of the Social Security Act, which applies only to the provision of home and community-based services for elderly persons. In essence, under a Section 1915(d) waiver program, a state is permitted to expend a specified amount of Medicaid dollars on home and community-based services, and this amount is increased in subsequent years according to an indexing formula. The major advantage (compared to the existing Section 1915(c) waiver authority) is that, within the expenditure limit specified in its approved waiver program, a state is free to provide HCB services to as many recipients as it desires. In other words, a state may reprogram all savings associated with reduced institutional (nursing home) costs to expand home and community-based services for Medicaid eligible elderly persons (see additional details on this special waiver authority in Appendix D).

Advantages. The fiscal viability of the Section 1915(d) waiver approach is closely tied to: (a) the adequacy of the indexing rate; and (b) the extent to which a state is capable of achieving comparative reductions in institutional costs. Assuming that satisfactory accommodations could be achieved in these two areas, the Section 1915(d) waiver formula should be far superior to the existing methods HCFA uses to control expenditures under Section 1915(c) waivers, since it: (a) avoids a federal cap on the number of waiver participants; and (b) allows states to recapture all savings associated with reductions in institutional costs and redeploy such dollars to expand home and community-based services. Keep in mind that the basis for calculating institutional savings is, in effect, established by law as part of the indexing formula. Since, according to the calculations of the Congressional Budget Office, Medicaid ICF/MR outlays have increased at a rate of approximately 11-5 percent over recent years, it is possible for Congress to permit a

In this regard, it should be pointed out that, while there are numerous problems associated with the institutional needs test, such a requirement would not prevent a state from vastly expanding access to HCB services under a state plan option, since, presumably, HCFA would no longer be in a position to Emit, administratively, the number of persons participating in such services according to the current and projected number of ICF/MR beds.

rather healthy rate of growth in overall Medicaid outlays while still finding the approach to be "cost neutral".

Since a new waiver authority undoubtedly would have to be justified on the basis of cost neutrality, it should be much easier to convince a budget conscious Congress to enact such legislation than it would be to add new optional or mandatory state plan coverages. The fact that the precedent for such legislation has already been established in Section 1915(d) should facilitate even further legislative consideration of a parallel waiver authority for MR/DD services. :

Disadvantages. While a Section 1915(d)-like waiver authority would deal with some of the major problems associated with the existing Section 1915(c) waiver program (i.e., by removing federal utilization controls and permitting states to redeploy institutional savings in the community), it would leave in place most of the other legislative and administrative constraints associated with the current operating framework of a waiver. Thus, for example, a state still would have to receive Secretarial approval of its waiver request as well as periodic renewals of its program. Officials in the one state that has applied for a Section 1915(d) elderly waiver thus far report that they are encountering the same frustrations, delays and uncertainties that other states have encountered in negotiating Section 1915(c) waiver requests with HCFA. The principal lesson may be that, as long as the authority to approve or disapprove a waiver request remains in the hands of an Administration that has as its primary goal containing the growth in federal Medicaid outlays, HCFA officials will be in a position to impose substantial roadblocks to accessing additional federal Medicaid dollars for home and community-based services.

Furthermore, any reform strategy that relies solely on reformatting the HCB waiver authority will leave unresolved other key Medicaid policy issues that potentially could undermine a state's capacity to pursue its fundamental, underlying goals. For example, unless substantial changes are made in existing ICF/MR policies a state could be trapped in a position where it has increased latitude to deliver home and community-based services but little control over the costs of ICF/MR services as a result of the impact of new federal regulations combined with continued "look behind" reviews. As a result, the state, despite its philosophical commitment to expanding community-based services, might not be in a position to take advantage of a Section 1915(d)-like waiver program, because the primary factors which influence ICF/MR expenditures are outside its sphere of influence.

It is also important to recognize that some states are in a better position than others to function successfully with the type of aggregate expenditure cap authorized under Section 1915(d). Generally, the higher a state's proportional share of total Medicaid expenditures on behalf of persons with developmental disabilities, the

more likely it is to find a Section 1915(d) cap an acceptable policy option. The net result is that this approach probably would be of greatest benefit to states that are already comparatively heavy users of Medicaid dollars. Certainly, it can be expected to do little to narrow the wide variations that currently exist in state Medicaid utilization levels on behalf of persons with developmental disabilities -- and may even exacerbate the present situation.

Finally, a Section 1915(d) approach to reforming Medicaid is certain to be criticized by consumer and provider interest groups. They will view it as a timid response to the pressing need for a basic restructuring of Medicaid coverage and benefits on behalf of persons with severe disabilities. In addition, they will be concerned that legislation of this type would blunt the long-standing efforts by consumer and provider interest groups to enact broader scaled changes in applicable Medicaid law.

4. Summary

Present federal policies limit the types of specialized Medicaid-reimbursable services that a state may furnish to persons with developmental disabilities to the ICF/MR program or alternatives (in the form of an HCB waiver program) thereto. Broadening the array of Medicaid-reimbursable services to include a wide range of supportive services represents a critical objective for all who are interested in reformulating current policies. As in the area of eligibility policy, how to achieve such a broadening without raising the specter of fiscal irresponsibility is a thorny problem.

C. Regulating and Monitoring Medicaid-funded Community Services

The regulation and monitoring of services furnished on behalf of persons with developmental disabilities is often given less attention in policy formulation than it deserves. These activities have bearing on three key dimensions of policy:

The standards against which monitoring of services is carried out define the very character of the types of services to be furnished to eligible individuals. Depending on whether "comprehensive care" or "supportive" service models are adopted as the paradigms under which standards are developed and checked against, the tenor of service delivery will be greatly affected.

The selection and articulation of standards has direct bearing on the costs of services and, consequently, the potential federal and state fiscal impacts of a reform proposal.

- Whether standard development and program oversight are viewed as a principally state or federal area of activity affects the degree to which states and communities are empowered to put into place unique perspectives regarding appropriate directions for service delivery.

How various issues in this arena are resolved, then, can have enormous influence on future directions in the delivery of publicly-financed services on behalf of persons with developmental disabilities.

1. Current Policy

Under the Medicaid home and community-based waiver authority (Section 1915(c) of the Social Security Act), a state is required, as part of its waiver request, to spell

out the steps it will take to protect the health and welfare of waiver participants. Although these quality assurance provisions are subject to the approval of the Secretary (along with all other aspects of a state's HCB waiver proposal), HCFA has allowed each state a considerable degree of latitude in designing its own unique approach to regulating and monitoring the delivery of HCB waiver services.

HCFA monitors a state's compliance with the terms of its approved waiver proposal by conducting an annual, on-site assessment of the program. One aspect of this assessment is an examination of whether the state's methods of protecting the health and welfare of waiver participants are effective. In addition, once every three to five years, a state must arrange for a third party evaluation of its HCB waiver program. The findings and recommendations resulting from this evaluation must be forwarded to HCFA at least 120 days prior to the date on which the current waiver period is scheduled to expire. HCFA generally will not approve a request to renew a waiver program until it has received a copy of such an independent evaluation report on the subject waiver program.

Similarly, states that elect to use other non-institutional Medicaid state plan coverages to support community-based services for persons with developmental disabilities (e.g., clinic services; personal care; medical rehabilitation services; etc.) are primarily responsible for developing and monitoring compliance with regulations governing the provisions of such services. This approach contrasts sharply with Medicaid policies governing ICF/MRs and other institutional service providers, where the federal government (i.e., HHS/HCFA) issues detailed operating standards and, increasingly, validates the accuracy of state decisions in enforcing those standards.

2 Unresolved Issues

The key issues to be resolved in the area of regulating and monitoring community services is the nature and extent of federal participation in the process. In other words, should standards be developed and enforced by the federal government? Or, should states be responsible for developing their own standards and, if so, to what extent should the federal government, either via statutory law or regulations, influence the content of such state regulations? A closely related issue involves the distribution of responsibility between the federal government and the states for monitoring compliance and enforcing community service standards in Medicaid-funded programs.

It is important to recognize that one of the significant byproducts of the federal ICF/MR look-behind initiative has been a growing national perception that the states, by and large, cannot be trusted to oversee the quality of services provided to persons with developmental disabilities. In a severely constrained fiscal environment, the fear is that the states will permit existing service programs to deteriorate, when faced with the unenviable task of balancing the pressure for further, rapid expansion in community-based services against the need to maintain the quality of present programs. Therefore, a strong federal role in standard setting and oversight, critics contend, is absolutely essential, since state governments only become concerned about the quality of services when they are threatened by severe federal sanctions. While this perception may be simplistic, it is a factor that cannot be ignored in evaluating the policy context within which national discussions of future Medicaid funding of community DD services are taking place.

Nor can one overlook the influence of events in other related areas of human services. For example, Congress' primary motivation for enacting nursing home reform legislation in 1987 (Subtitle C, Title IV, P.L. 100-203) was to correct the perceived shortcomings in state and federal enforcement of standards in Medicare and Medicaid-certified nursing homes (Gettings et al., 1988). Similarly, the problem of homelessness among persons with chronic mental illness is viewed in Washington as a prime example of the failure of states generally, and state/local mental health

agencies in particular, to manage services to a highly vulnerable group of citizens. While events in these areas of policy have no direct bearing on the past or future performance of the states in monitoring the delivery of quality services to persons with developmental disabilities, they do affect the general perceptions of federal policymakers and the way in which they are likely to balance national and state interests in any broad-based piece of Medicaid reform legislation.

At the same time, Congressional and Executive Branch leaders are **aware that: (a)** a strong-federal oversight role is far from a guarantee that quality services will be delivered by providers of Medicaid-funded programs; and (b) there are finite limits on the role the federal government can play in the quality assurance arena. **First, while,** arguably, it may be feasible for the federal government to assume direct responsibility for surveying and certifying ICF/MR facilities (or at least state-operated ICF/MRs, as proposed in the Waxman bill), it is inconceivable that primary responsibility for overseeing a diverse, widely dispersed **and growing network** of community-based **DD** services would be "federalized" by Congress, given federal personnel constraints and the massive logistical and financing problems such a move would entail.

Second, while a return to a laissez-faire federal oversight role does not appear to be on the horizon, it is not clear that Congress is willing to grant the Department of Health and Human Services sweeping new authority to establish and enforce federal standards. Indeed, the 1987 nursing home reform legislation is as much a condemnation of the lack of effective federal oversight as it is a reflection of the states' failure to carry out their survey/certification/enforcement responsibilities. The basic approach of P.L. 100-203 is to prescribe in much greater detail, the statutory standards that are to be enforced in Title XVIII and Title XDC-certified nursing homes and the procedures the states and the Secretary are to follow in carrying out their respective responsibilities. It is worth noting that the Waxman Medicaid reform bill would adopt exactly the same approach to regulating ICF/MRs (see Appendix B for details).

While there are a variety of ways of structuring the federal government's role in assuring the quality of Medicaid-assisted community DD services, one fundamental problem that must be grappled with is the lack of a clear consensus within the field concerning the most appropriate methods of assessing program effectiveness or quality. There is a growing recognition among DD service providers, consumers and state officials that, while input and process requirements can and should play a role in assessing a program's or facility's compliance, ultimately outcome-based criteria are needed to gauge the overall effectiveness of DD services. Yet, despite a sharp increase in the use of outcome measures in recent years, no consensus has emerged to date on the precise measures that should be employed or the best methods to use in evaluating program effectiveness. It seems fair to conclude, therefore, that the state-of-the-art in the area of quality **assurance is in flux. What appears to be emerging is an agreement that a variety of perspectives on program quality need to be examined in order to gain a multi-dimensional understanding of the effectiveness of a service program. The exact mix of assessment tools and techniques that should be used as part of such a quality assurance program, however, are still a matter of debate.**

In view of the current uncertain status of quality assurance methods, the thought of imposing a new set of federal requirements governing the provision of Medicaid-supported community services is enough to cause any thoughtful observer to pause. A better-defined and expanded federal oversight role may be the price states have to pay for a more reliable basis to claim Medicaid reimbursement for community-based DD services; however, unless this role is very carefully delineated, the imposition of a uniform set of national operation assumptions and requirements could have a stultifying effect on the evolution of new and more effective service techniques and programming formats.

3. Proposed Solutions

The possible approaches to regulating and monitoring community programs might be summarized as follows:

- a. Require each state to develop a comprehensive quality assurance program that meets federal statutory specifications, including the promulgation of state standards governing each Medicaid-reimbursable element of community-based services it offers under its state Title XIX plan. This is the approach taken in the Chafee/Florio bill. Under the terms of S.1673/H.R.3454, a state would be required, as part of its "state implementation strategy", to spell out a comprehensive quality assurance system. One mandatory element of this system would be state standards designed to assure that Medicaid-reimbursable services were based on timely assessments of individual needs, furnished in accordance with individualized plans, provided in community settings and designed to facilitate community integration. In addition, states would be responsible for licensing or certifying all facilities and programs that provide Medicaid-reimbursable community and family support services and would have to establish systems for conducting "annual, independent, third-party evaluations of a cross-section of community and family support services", as well as methods for assessing consumer satisfaction with such services.

The Secretary of HHS, under the provisions of the Chafee/Florio bill, would be responsible for reviewing a state's plans for instituting a comprehensive quality assurance system. The Secretary also would be charged with conducting periodic assessments of the status of individuals with severe disabilities who were receiving community services under each state's Medicaid plan. However, the Secretary would be prohibited from promulgating federal standards governing the operation of Medicaid-reimbursable community and family support services.

Advantages. This general approach, it could be argued, strikes a reasonable balance between federal and state interests in assuring that Medicaid-funded community DD services comply with minimum program standards. Federal law would spell out, in considerable detail, the elements that a state would be required to have as part of its comprehensive quality assurance system. However, a state would have flexibility in deciding how to perform such functions.

This approach would avoid the "one size fits all" system of standard setting and compliance that currently exists in the ICF/MR program. Consequently, as experience with the HCB waiver program will substantiate, each state is likely to find it much easier to integrate Medicaid-reimbursable elements of services into its existing community service system. In addition, the states would find it much easier to foster the kind of innovation and creativity that has been demonstrated in some Medicaid home and community-based waiver programs.

Finally, by avoiding the imposition of detailed federal standards, it should be possible for the states to deliver a wider array of services in a more cost-effective manner. Experience "with federal ICF/MR standard setting suggests that uniform national standards tend to introduce rigidities that add significantly to the cost of delivering

services, without achieving any measurable benefits to the recipients of such services.

Disadvantages. The absence of a direct federal oversight role will be viewed with considerable skepticism by many consumers, and providers, who see tough federal standard setting and monitoring as the sine qua non of high quality programming. They will point to the events of 1984-85 that led to the initiation of an expanded series of federal ICF/MR look behind reviews as proof that the states cannot be trusted to monitor program quality. Such arguments can be expected to receive a sympathetic hearing in Congress and among Executive Branch officials, both of whom tend to believe that a pro-active federal role is essential if high quality programming is to be maintained.

Furthermore, to the extent that one places a relatively higher priority on uniformity of program quality across political jurisdictions, federal standards may be the only means - certainly the most direct means - of achieving this end. Regardless of one's views regarding the relative merits of federal standards, it is hard to argue that state discretion in this area would not lead to greater interstate variations in the types and quality of services provided to persons with developmental disabilities.

- b. Require all providers of community habilitation services to meet standards promulgated by the Secretary of HHS. This, in essence, is the approach proposed in Congressman Waxman's bill. According to H.R. 5233, the Secretary would be obligated to promulgate standards governing residential providers of "community habilitation services" no later than October 1, 1989. These standards would have to include provisions governing client rights and protections, case management, the completion of comprehensive functional assessments, the process of developing, monitoring and updating individual program plans, the use of a uniform client performance accounting system and the application of minimum health, safety and sanitation rules.

In addition, the Waxman bill contains a separate requirement that the Secretary develop and promulgate, by January 1, 1991, outcome-oriented evaluation methods/instruments. The states, in turn, would be obligated to use such methods/instruments in evaluating Medicaid-reimbursable community habilitation services after July 1, 1991. It is unclear how this provision would intersect with the requirement described above; however, in general, the bill would delegate to the Secretary rather broad authority for establishing standards governing Medicaid-reimbursable community services.

Advantages. As noted above, federal standards would promote greater nationwide consistency in the delivery of community services. Thus, if one places a high priority on achieving nationwide uniformity and consistency in the provision of such services, a strong case can be made for promulgating federal community service standards. Provider and consumer interest groups who are dissatisfied with existing state standard setting and monitoring procedures, therefore, can be expected to support this approach, since they will view federal standards and compliance reviews as a way of leveraging state action in this area. The promulgation and enforcement of

federal standards would also assuage the concerns of individuals who believe that the states cannot be trusted to deliver safe, appropriate and high quality services in a manner that fosters their dignity and independence.

- * Disadvantages. Recent experience with federal standard setting in the area of ICF/MR policy strongly suggests that the promulgation of federal community service standards would result in: (a) a monolithic nationwide approach to delivering community residential and daytime services at a time when the field's emphasis has shifted to creating a wider array of more individualized living and programming arrangements; and (b) a clinically driven model of services that ultimately would increase the cost of operating Medicaid-funded residential and day programs substantially, without necessarily achieving any measurable improvements in the quality and appropriateness of the services provided.

Under this approach, the Secretary of HHS would be granted broad new authority. Such authority, in the hands of a hostile Administration (i.e., one with an overriding objective of cutting Medicaid costs) could lead to the promulgation of standards designed to impede the states' efforts to claim increased federal Medicaid reimbursement for eligible community-based services.

Finally, the imposition of a set of federal community service standards, coupled with an expansive federal oversight role, could dissuade states from covering optional community habilitation services, as proposed under the Waxman bill. The net effect would be to thwart the basic underlying goal of the legislation — i.e., to minimize the institutional bias of current Medicaid policy.

- c. Authorize the states to promulgate standards governing each category of community-based services they elect to cover under their Title XIX plans, but spell out in federal law the specific elements that must be included in such standards. This approach is similar, at least in theory, to the ASPE/HHS proposal. It would use federal law to specify the areas that would have to be covered in state community service standards, but stop short of indicating precisely how each subject area must be regulated. The latter task would be left to the discretion of each individual state.

- Advantages. This approach, it could be argued, would strike an appropriate balance between the role of the federal government and the role of the individual states in regulating service quality. The broad framework of community standards would be set forth in law, while the individual states would be required to "fill in the details". Assuming, for the moment, that the Secretary was authorized to monitor and report on the state's performance in this area, it would be possible to add further federal statutory specifications at any time it became clear that such additional requirements were necessary. This "minimalist" approach to legislating standards would permit the states to retain considerable discretion in establishing standards and maintaining compliance, at least to the extent that they performed such functions adequately. However, it also would give Congress a

means of intervening to correct any shortcomings in state quality assurance programs, if and when they occurred.

Disadvantages. It is not clear that this approach would satisfy critics of the states' past and current quality assurance efforts. Nor is it clear that it is possible to gain agreement on what constitutes legitimate federal statutory specifications vs. federal requirements that, in effect, dictate the specific contents of state standards.

- d. Require providers of Medicaid-reimbursable home and community-based services to be accredited by a recognized national accrediting body in order to qualify for Medicaid reimbursement of such services. This "deemed status" approach has been recommended by supporters of national accreditation programs for at least ten years. It also is part of ASPE/HHS's pending Medicaid reform proposal. The basic argument in favor of officially recognizing accreditation as tantamount to a federal "seal of approval" is that, if an objective, qualified third party assessment team conducts provider performance reviews, quality assurance decisions can be insulated from the political arena and, therefore, arrived at on a fairer, more professional basis.

- Advantages. If one accepts the notion that both the states and the federal government have a vested interest in the outcome of compliance reviews, then it follows that a disinterested third party review is a potentially useful — some would argue the only — means of assuring that the ultimate beneficiaries of such services remain the overriding focus of quality assurance reviews. Besides, many providers of residential and day services report that accreditation surveys (unlike state and federal licensing/certification reviews) serve as an important learning experience and validation technique for their staffs.

Disadvantages. Since decisions regarding the eligibility of programs/facilities to provide Medicaid-reimbursable services have political ramifications, some observers would argue that such decisions should not be removed from the political process. Federal and state elected officials ultimately serve at the pleasure of the electorate and, as such, should be accountable to the public. An accrediting body, no matter how qualified, can never act as a substitute for political judgement in our pluralistic society. Besides, past experience in granting "deemed status" to accreditation programs under federal law suggests that once such programs take on a quasi-official function, their objectivity is often compromised. Consequently, while accreditation may play an important role in a state's overall quality assurance program — even to the point of serving, at the state's option, as a substitute for state program reviews — it cannot act as a replacement for federal and state compliance monitoring.

Summary

Issues in regulating and overseeing Medicaid-reimbursable services furnished to persons with developmental disabilities are among the most difficult to address in the debate concerning how best to reformulate current federal policies. The discomfort that arises with many of the proposed solutions goes beyond classic issues in federalism to the fundamental fact that the entire question of how best to

establish and monitor standards for service delivery is itself an unresolved problem in the field.

D. Limitations on Medicaid Payments

Given the enormous complexities in predicting the potential fiscal ramifications of fundamental changes in federal Medicaid policies **as they** affect persons with developmental disabilities, the suggestion arises of employing limitations on federal payments to states as a means to assure predictable dollar outcomes of proposed policy changes. Such limitations might represent a means to unsnarl the gridlock that has forestalled the adoption of needed changes in federal policies.

1. Current Policy

Under current Title XIX law, the federal government shares in the cost of statutorily authorized services furnished to eligible persons. The level of Medicaid payments made to any given state to support DD services depends on the choices that a state makes regarding the scope of services furnished to eligible persons, how much a state decides to pay for such services, the eligibility parameters established by the state, and the service delivery system's capacity to furnish authorized Medicaid-reimbursable services. In the area of federal payments to the states, Medicaid law/regulations proscribe the boundaries of Title XIX participation in the costs of services; within these boundaries, a state has the discretion to determine -- based on its own circumstances, system management objectives, and fiscal considerations - the degree to which federal aid will be employed to support persons with developmental disabilities. Federal financial participation, then, represents the interaction between federal policies and state choices.

The enactment of the HCB waiver authority in 1981 introduced an important change in federal Medicaid policy. Previously, federal law mandated that a state "entitle" all eligible persons to any state plan services they needed. The law also provided that the federal government would participate in all allowable costs of furnishing services covered under a state's Title XIX plan. Under the HCB waiver authority, however, a state was offered the option of supporting home and community-based service alternatives if it agreed to restrict its claims for federal reimbursement to no more than the cost of institutional services that would otherwise have been furnished to persons needing long-term care services.

HCFA administrative policies governing HCB waivers, initiated to curb rising long-term care expenditures on behalf of persons with developmental disabilities, not only limit per capita expenditures on behalf of eligible persons but also restrict the number of persons who may receive long-term care services, whether in an institutional (Le., ICF/MR) setting or **in an HCB waiver program. As a consequence, a state may furnish alternative, community-based services only** if it is willing to accept limitations **on federal payments and the number** of individuals who receive Medicaid-reimbursable long term care services.

At present, 39 states operate specialized **long term** care services for persons with mental retardation and related conditions under such a waiver-induced funding cap. In other **words, the** attractiveness of furnishing **HCB** services has prompted three-quarters of the states to accept a limitation **on federal payments, a** limitation that is unique within the Medicaid program. States which do not operate HCB waiver **programs may increase the number of eligible recipients as well as related federal reimbursement** claims, limited only by **applicable federal policies; but they may not claim reimbursement** for services that **are not authorized as** state **plan** coverages federal **law, regulations and** guidelines.

2. Unresolved Issues

An oft-cited reason for reforming federal Medicaid policies as they affect persons with developmental disabilities is that such policies result in federal dollars flowing to support a relatively small number of individuals in inappropriate and expensive settings. Indeed, 95 percent of Medicaid support for specialized DD long-term care services is channelled to the ICF/MR program, where 87 percent of all persons served reside in large congregate care facilities. Hence, one motivation for Medicaid reform is to permit dollars currently directed to supporting congregate services to be redirected to support family and community-based services, where federal assistance might be used more cost effectively to fund services to additional unserved and underserved persons.

While broadening the types of services that are eligible for Medicaid funding is a common goal of nearly all parties associated with the DD service delivery system, broadening the scope of Medicaid-reimbursable services (particularly when the subject legislation also would expand eligibility for such services) could have enormous fiscal consequences for both the states and the federal government. With federal Medicaid expenditures for DD long-term care services already rising at an annual rate of 11.5 percent, the prospect of expanded opportunities for states to claim additional federal reimbursement could well run counter to efforts in Washington to curb the federal deficit. Given this context, employing some type of limit on federal Title XIX payments to the states, arguably, may be a way of creating a sounder basis for the provision of services to persons with developmental disabilities, while at the same time remaining within politically acceptable boundaries governing the future rate of growth in related federal Medicaid outlays.

The fundamental issue in this area of policy is the extent to which Medicaid reform legislation should be aimed at redirecting current Title XIX expenditures to home and community-based programs, as opposed to expanding the number of persons with developmental disabilities who receive federally-assisted services. A related issue involves the basis upon which federal dollars are to be distributed to the states. There are substantial variations in how states currently employ Medicaid dollars in their DD service delivery systems. Proposals to limit future federal payments, therefore, must confront the current uneven distribution of related Medicaid funds among the states.

3. Proposed Solutions

While a wide variety of alternatives potentially exist in this area of policy, the possible approaches might be summarized as follows:

- a. Freeze federal financial participation (FFP) in the cost of operating large ICF/MRs (i.e., facilities with 16 or more beds), while leaving existing policies governing small, community-based ICF/MRs intact. This is the approach proposed in the Chafee/Florio bill. The basic rationale is that the overarching goal of the legislation (i.e., to foster a shift toward a community-centered service delivery system) would be accomplished if the states were faced with explicit financial incentives to continue to reduce the number of residents in large ICF/MRs. In addition, the FFP savings that would be achieved by capping federal payments to large ICF/MRs would help to offset the increased costs associated with the bill's proposed new community-based service coverages.

Advantages. This approach clearly would place additional pressure on the states to downsize large ICF/MR-certified facilities, since they would be forced to replace federal dollars with state general funds unless the state-wide census was reduced at a rate that permitted facilities to remain within current budgetary levels. Since most

states are in the process of reducing their reliance on large, multi-purpose institutional facilities and concurrently expanding community-based services anyway, it could be argued that a cap on federal payments to large institutions would simply reinforce this existing policy direction. Certainly, the legislation would grant the state much wider latitude in claiming Medicaid reimbursement for a broad range of family and community-based services. To the extent that a state already furnishes some of these services without Medicaid assistance, it should have an established base of matching funds and, therefore, be able to finance a rather rapid expansion of community and home-based alternatives to institutional care.

In addition, because budgetary impact will be a key factor in determining the fate of any Medicaid reform legislation, the savings associated with the cap should make it considerably easier to justify an expansion in Medicaid coverage of community-based DD services.

Disadvantages. Critics of the Chafee/Florio bill usually cite the cap on institutional payments as the principal reason why they are opposed to the legislation. Key Congressman and Senators also oppose a cap on institutional Medicaid expenditures, because they believe it would set a precedent that could lead to further reductions in Title XIX benefits. In summary, it seems clear from the debate surrounding the legislation that it will be difficult, if not impossible, to enact Medicaid reform legislation that includes a Chafee-like limitation on payments to large ICF/MR facilities.

Looking beyond the question of the political feasibility of capping federal payments to large institutions, one must examine the likely impact of a cap on state fiscal policy. As long as a state was in a position to reduce its institutional population at a rate that would permit it to keep expenditures in large ICF/MRs within the freeze level, a payment cap would have little if any impact on the state's capacity to expand community-based services at a pace sufficient to absorb persons displaced from institutional settings. Since states have been reducing their institutional populations at a rate of 4 to 7 percent annually over the past ten years, theoretically this goal should be achievable.

However, the fact that states have less control over ICF/MR expenditures today than they had three or four years ago adds a new, unpredictable element to the decisionmaking equation. The open-ended requirements of HCFA's new regulatory standards, as interpreted and enforced through federal look-behind reviews, could easily lead to a rapid escalation in the cost of operating ICF/MRs. Under such a scenario, many states might find it impossible to offset such cost increases through further reductions in ICF/MR facility populations. A freeze on FFP related to the costs of operating large institutions under these circumstances would force a state to divert state general revenue dollars, which otherwise would be used to expand and improve community-based DD ser-

vices, to rectify ICF/MR deficiencies. As a result, policymakers in many states could find themselves in a position where they were unable to fulfill the basic aims of the legislation, even if they were philosophically committed to doing so.

While undoubtedly the provisions of the Chafee/Florio legislation would offer more reliable access to Medicaid funding for family and community support services than is possible under current law, the potential state and federal budgetary ramifications of the legislation are highly uncertain. Administration estimates of the fiscal impact of the legislation suggest that the bill would increase federal Medicaid spending by \$1.3 billion, or approximately 20 percent. In the context of development of the federal budget, executive branch disagreement with CBO estimates of the bill's fiscal impact could influence whether the legislation is enacted.

For states, both the short and long-term ramifications of the bill are difficult to estimate. The "entitlement" provisions of the legislation introduce a potential "wild-card" into state budgetary planning. If broadened access to Medicaid-reimbursable family and community support services is translated into substantially higher demand for such services, then a state may find that its pool of currently unmatched dollars is rapidly exhausted and a significant increase in state appropriations would be necessary. In order to guard against such an outcome, a state might find it necessary to pursue conservative implementation strategies, a course that might hinder the achievement of the overarching objectives of the legislation.

In addition, to the degree that such conservative strategies are implemented, the CBO scenario of a net reduction in federal aid might come to pass, an outcome that ultimately would result in reduced services. Instability in a state's community service budget could lead elected state officials to call for the same types of "cost containment" measures that have afflicted Medicaid health care programs during the 1980s. Hence, it is not entirely clear that providing uncapped reimbursement for community-based services, while simultaneously entitling a broader population of persons with developmental disabilities to services, would serve the long-term interests of the states or people in need of such services.

Finally, the Chafee/Florio legislation does not attempt to address the problems associated with the current uneven distribution of federal Medicaid funds nationwide or the variations in state support for DD services. The differing positions of states with regard to the use of Medicaid dollars, as well as the varying levels of state contributions to support such services, means that the opportunities (or potential drawbacks) presented by the legislation will differ from state-to-state. While the legislation could provide important opportunities for low-spending states to gain additional federal dollars, it is not at all clear that such an outcome could be guaranteed.

- b. Continue the traditional approach to federal participation in the costs of authorized Medicaid services by imposing no cap on federal payments for services. The Waxman bill would allow a state to choose to escape the caps presently imposed on HCB waiver programs by opting to cover community habilitation services under its state Medicaid plan. Hence, conventional Medicaid policies would be reasserted in this area of the Title XIX program. This approach also reflects the long-standing opposition of Representative Waxman and other key House members to the imposition of a cap on any segment of Medicaid expenditures, a position that has been reiterated many times, particularly in response to *the* Reagan Administration's repeated attempts to impose an overall ceiling on federal Medicaid payments.

The approach in HLR.5233 also reemphasizes the fact that the Medicaid program is premised on a state's selection of optional service coverages authorized by Congress. As a consequence, a state could increase its spending (by opting to cover community habilitation services) or limit its spending (by opting not to do so and, possibly, maintaining a HCB waiver program).

Advantages. Considered solely on the basis of the degree of discretion afforded the states, the Waxman bill, in comparison to the Chafee/Florio legislation, obviously would permit a state to exercise greater control over the use of Medicaid funds for community-based services. No limits would apply to federal financial participation for either institutional or community-based services. Hence, a state would be partially protected from the fiscal ramifications of increased federal scrutiny of ICF/MRs (i.e., the federal government would participate in its share of the increased costs of such services). A state could regulate the scope and range of community habilitation services and, consequently, exercise greater control over this segment of its budget. Expansion of community-based services would occur at a pace determined by state policymakers, rather than being driven by entitlement provisions that are difficult to manage.

In addition, while CBO has attributed a positive fiscal impact to the Waxman bill, its estimate of the additional costs associated with implementing the legislation is relatively modest and should not pose such a serious impediment to enactment of the legislation.

Disadvantages. In some respects, the disadvantages of this legislation parallel those attributable to the Chafee/Florio bill. For example, even though payments for services in larger ICF/MRs would not be capped, the fact remains that, in the absence of predictable ICF/MR costs, state MR/DD budgets may still be destabilized by increased federal regulatory oversight. In addition, interstate distributional concerns paralleling those attributable to the Chafee/Florio bill would be experienced under the Waxman legislation. Indeed, should this legislation be enacted, it can be argued that the present, uneven distribution of both state and federal funds supporting DD long-term care services nationwide might be accentuated, thus leaving unaddressed critical

concerns about differential access to services by persons with developmental disabilities.

In addition, it can be noted that the Waxman bill introduces its own wild-card into the state-federal fiscal equation: namely, increased federal oversight of community-based services. To the degree such oversight might lead to increased program expenditures, a state's community services budget may be destabilized, with the state faced with the Hobbesian choice of maintaining current services at the expense of broadening the number of individuals receiving services.

- c. Create an entirely new approach to financing DD long-term care services by employing an indexed, formula-based grant-in-aid approach to distributing federal dollars to the states. Three Medicaid reform options have been suggested which attempt to link greater state flexibility in employing Title XIX funding on behalf of persons with developmental disabilities to the use of a limitation on the overall level of federal financial assistance. These proposals are:

New York's 1985 proposal to index federal Medicaid payments for developmental disabilities services to inflation plus population change, while offering those states that do not employ Medicaid financing extensively additional federal assistance in expanding services. The New York proposal was premised on a concomitant relaxation of federal regulation of programs.

- . ASPE/HHS's proposal to remove specialized MR/DD benefits completely from the Medicaid program, give each state a base level of federal assistance indexed to inflation, and provide additional funding to those states that receive federal payments below the national mean for all participating states.

The Section 1915(d) waiver authority enacted by Congress as an optional means by which states may furnish HCB services to elderly persons; as previously indicated, this authority indexes a state's present level of federal assistance to changes in prices and population but permits a state to shift dollars away from institutional services to home and community-based services without any restrictions on the number of persons who may be served (as is the case under the existing Section 1915(c) waiver authority).

A consistent theme that runs through proposals of this type is that decoupling payments to states for the provision of DD services from Medicaid's customary funding mechanism represents a reasonable means of trading off greater state flexibility for better control over future federal outlays. While each of these proposals employs a different mechanism to accomplish this trade-off, they are each premised on the notion that Medicaid reform requires a fundamental rethinking of how federal dollars flow to states.

These proposals may be distinguished from one another by the degree to which federal policies would dictate the types of persons who receive federally-assisted services and by the federal government's role in overseeing state programs supported by federal dollars. The Admin-

istration's proposal, for example, would mandate that participating states serve all persons with severe and profound disabilities and furnish them with a minimum array of services. The proposal also includes a proactive federal role in regulating the quality of services furnished by states. The New York proposal, on the other hand, is premised on reducing the degree of federal intrusion into state programs. A Section 1915(d)-like waiver authority, by contrast, simply would allow states to repackage current dollars without altering other areas of federal-state relations within the context of the Medicaid program.

Advantages. Few knowledgeable observers would argue that there are significant trade-offs between federal funding levels and the ability of states to control the scope and range of DD services provided. Undoubtedly, many states would be willing to exchange controlled rates growth in federal Medicaid receipts for enhanced capability to manage and direct the provision of services.

In addition, any of the various alternatives used to implement this approach would have a neutral impact on the federal budget deficit. By contrast, proposals that utilize Medicaid's current financing framework can have a highly uncertain fiscal impact, as pointed out in the discussion of some of the earlier options.

Disadvantages. At the same time, however, this generic approach poses many potential difficulties, including:

Interstate Variations. Tying future federal assistance to current Medicaid spending levels (i.e., in order to hold harmless all states initially), while indexing the future rate of increase in total federal outlays, could lock in existing interstate variations in the distribution of federal assistance, along with the obvious inequities associated with these variations. On the other hand, equalizing assistance among the states would be very expensive and, ultimately, would affect the attractiveness of such proposals from a federal budgetary perspective.

Quality Assurance Issues. To the extent that the federal government has a far-reaching role in overseeing provider performance (in both ICF/MRs and community-based service settings), a state's acceptance of a limitation on federal aid would substantially increase its financial risk. Vigorous enforcement of federally-mandated program standards would leave a state liable for paying 100 percent of any increase in the costs of services (i.e., beyond its fixed federal allocation level). Federal control of program standards, in effect, would leave control over program costs in **the** hands of the federal government, which would **not** be financially accountable for its actions.

Entitlement Issues. The viability of proposals to limit federal assistance is directly related to the conditions a state would have to meet to provide a defined array of services to specified classes of

persons with developmental disabilities. Attaching entitlements to a closed-ended funding program (as would occur under the ASPE/HHS proposal) poses enormous financial risks for the states.

Thus, while it is legitimate to discuss trade-offs between funding levels and enhanced state flexibility in pursuing cost effective options for serving persons with developmental disabilities, the viability of any proposal depends on how it addresses each of the foregoing issues.

Summary

While the concept of trading off (in whole or in part) the "openendedness" of Medicaid-financing in order to achieve other policy aims is a nominally attractive solution to the potential fiscal problems entailed by Medicaid reform, each of the potential solutions that have been offered thus far engender difficult policy problems in their own right. In addition, it seems clear that a coherent strategy in this area must recognize that it is extremely difficult to develop viable solutions that address the problems faced by states in a holistic fashion.

E. ICF/MR Policies

Current federal regulations governing the ICF/MR program at once stand as a major factor spurring the need to reformulate federal Title XIX policies as well as a particularly critical element in any effort to adopt coherent, holistic policies ranging across all types of Medicaid-reimbursable services furnished on behalf of persons with developmental disabilities.

1. Current Policy

Under existing law, a state may certify a facility as an intermediate care facility for the mentally retarded (ICF/MR) if it is capable of providing active treatment services to persons with mental retardation and related conditions and is found to be in compliance with standards promulgated by the Secretary of Health and Human Services (Section 1905(d) of the Social Security Act). Revised ICF/MR standards were published by HHS on June 3, 1988 (53 FR 20447), with an effective date of October 3, 1988. As the first major rewrite of federal ICF/MR policies since Secretarial standards were initially released in 1974, the June 3 revised regulations contain potentially far-reaching modifications in prior policy. Among the most significant changes are:

Federal regulatory requirements have been reorganized into a series of eight "conditions of **participation**", **in order** to improve the objectivity of the compliance assessment process, according to HCFA/HHS officials;

The emphasis has been shifted from process-oriented requirements and paperwork reviews to service outcomes, assessed through the direct observation of resident-staff interactions throughout the day, and

The revised regulations stress **the provision of "continuous, aggressive active treatment services" as the central organising goal of an ICF/MR facility.**

To supplement its new regulatory standards, **HCFA/HHS** also has published: (a) new interpretive guidelines which elaborate on the intent of particular regulatory requirements; and (b) revised surveyor forms, instructions and procedures that are keyed to the goal of assessing a facility's performance in terms of the actual delivery

of services to residents (HCFA Transmittal No. 212 to the State Operations Manual, dated October, 1988).

Although HCFA's June 3 regulatory standards are new, they represent a continuation of attempts by federal officials to change the basic approach to assessing an ICF/MR's performance that began when HCFA launched its expanded series of ICF/MR validation ("look behind") surveys in late 1984. Federal "look behind" surveys have had the effect of transferring enforcement authority from the states to HCFA. For while the states retain the basic authority under current law to determine whether an ICF/MR facility is complying with federal regulatory requirements, HCFA, through its ICF/MR look behind authority (Section 1910(c)(1) of the Act) has become the final arbiter of compliance.

Since the states are usually required to add staff or take other expensive corrective actions in order to respond to federal deficiency citations, the states also exercise less control over the operating costs of such facilities. The rapid increase in the per capita cost of providing ICF/MR services, therefore, can be viewed as an important side effect of the federal government's "look behind" initiative. If anything, publication of revised ICF/MR regulatory standards can be expected to accentuate this trend, since the new rules provide a firmer basis for HCFA's approach to assessing compliance and demand that state survey agencies adopt the same approach.

2. Unresolved Issues

The principal policy question that needs to be resolved is: are specific modifications in federal law applicable to ICF/MRs needed, as an integral part of Medicaid reform legislation, in order to facilitate holistic planning and program development within each participating state? In other words, can the oft-criticized institutional bias of Medicaid policy be eliminated (or, at least, substantially reduced) by expanding statutory authority to cover community DD services under state Medicaid plans, while leaving the existing legal basis for covering ICF/MR services unchanged?

In considering this question, it is important to keep in mind that roughly 95 percent of all federal Medicaid payments for specialized DD services are channelled through ICF/MRs. Given the effects of the new federal regulations, coupled with the ongoing impact of HCFA look behind reviews, the probability is high that the upward spiral in ICF/MR costs will continue. If so, many states are likely to find it difficult to expand community-based services further because of the necessity of maintaining the certification status of existing ICF/MRs.

One possible alternative available to the states is to emphasize the development of small, community-based ICF/MRs. Although this option has been used rather extensively by a number of states over the past ten years, certain features of HCFA's new ICF/MR rules will make it more difficult ~ and more expensive - to maintain the certification status of such facilities in the future. Furthermore, the fundamental precepts underlying the ICF/MR program are, in many ways, antithetical to philosophies that now underpin the delivery of community-based services. More specifically:

An ICF/MR must serve as the hub of a 24 hour array of services to its residents, at a time when the field of developmental disabilities is emphasizing a pluralistic approach to the provision of services;

The ICF/MR program is based on a strong clinical orientation to the delivery of services - an orientation that HCFA's revised operating standards strongly underscore - at a time when the field

is increasingly emphasizing greater independence for persons living in the community,

Federal regulations specify that ICF/MR services must be provided in congregate settings (i.e., four or more persons per residential site), when the field of developmental disabilities is moving toward more individualized living arrangements with appropriate supportive services; and

Medicaid regulations prohibit a state from claiming Title XIX reimbursement for vocationally-oriented services on behalf of ICF/MR residents at a time when most experts would agree that, with the exception of a relatively small number of adults with extremely complex disabilities, most persons with developmental disabilities can benefit from productive work, if the job tasks are appropriately structured and the proper supportive services are available.

Advocates of community-based services generally have rejected the precepts that underlie the provision of ICF/MR services (even though significant efforts have been made in some states, with mixed success, to accommodate those precepts to the overarching goals of community-based services). The basic question, therefore, is not whether any newly created Medicaid authority to support home and community-based services should be patterned after the ICF/MR model, but rather whether it is possible for such a new authority to co-exist with the ICF/MR program in the absence of any statutorily sanctioned method of bridging the philosophical and practical differences between two very different approaches to organizing, delivering and financing specialized long term care services for persons with developmental disabilities through the Medicaid program.

3. Proposed Solutions

The possible approaches to modifying ICF/MR policies can be summarized as follows:

- a. Require a state, as a condition of covering a specified array of home and community-based services under its Medicaid state plan, to provide assurances satisfactory to the Secretary that, within one year of the effective date of coverage of such state plan services, it will promulgate and periodically revise a long range implementation strategy for effectively utilizing Medicaid payments on behalf of persons with mental retardation and related conditions. This written implementation strategy would have to spell out a coordinated approach to using payments received under various Medicaid state plan options to serve such persons, including ICF/MR residents, participants in community-based services (either under an HCB waiver, a newly created state plan coverage or existing state plan options) and inappropriately placed nursing facility residents. In developing its implementation strategy, a state would be obligated to circulate a draft copy for public comments and hold public hearings to obtain feedback from interested individuals and organizations.
 - Advantages. The principal rationale for requiring each participating state to develop a long range implementation strategy is to ensure that: (1) an appropriate statutory framework exists in each state for making decisions regarding the use of Title XIX financing on behalf of persons with mental retardation and related conditions that encompasses all relevant aspects of Medicaid policy, and (b) various actors who have a stake in the provision of services to persons with developmental disabilities (i.e.,

provider agencies; parent/advocacy organizations; professional organizations; unions; etc.) have an opportunity to participate in the development of the state's future plans and policies as they relate to the utilization of Medicaid dollars. In the absence of an established method of bridging the philosophical and practical differences between Title XIX financing of ICF/MRs on the one hand and community-based services on the other, the current tensions that characterize the provision of developmental disabilities services in most states will be very difficult to resolve. The creation of a open, holistic planning process, in and of itself, would not necessarily lead to the resolution of these complex issues, but at least it would provide a more rational framework for confronting and solving such issues.

Disadvantages. Some will argue that Medicaid is, by its very nature, a financing program under which states have broad discretion to organize and deliver services as they see fit, provided basic statutory parameters governing client eligibility and the scope of permissible services are met; detailed planning requirements, therefore, simply are not compatible with the underlying purpose or historical aims of the program.

Such individuals will point out, quite correctly, that Congress has rarely, if ever, attached planning requirements as a condition of covering an optional Medicaid service, and argue that to do so in the case of specialized developmental disabilities services would create an inappropriate precedent within the overall operating context of the Title XIX program.

- b. Allow states, on an optional basis, to enter into an agreement with the Secretary to control future growth in ICF/MR costs. This approach would build on experience within the Medicaid home and community-based waiver program; however, instead of simply specifying projected census levels and average per capita expenditures of ICF/MRs, the state would negotiate with the Secretary a detailed, five-year plan for managing further reductions in ICF/MRs and expanding home and community-based services. This plan would specify not only the strategies, resources commitments and timetables the state would follow in reducing its reliance on ICF/MR beds and expanding the availability of home and community-based services, but also indicate the specific steps the state would take to assure that its ICF/MRs remained in compliance with federal operating standards.

If an ICF/MR were found out of compliance with federal certification requirements and the state as well as HCFA agreed that expenditures in excess of the amount contained in the state's projected ICF/MR spending for the given fiscal year would be essential to correct such deficiencies, the state's plan of correction would be subject to review by a national panel of experts before it was finally approved or disapproved by the Secretary. If such a correction plan were approved, all such "excess" expenditures would be subject to FFP at the state's regular service matching ratio. However, the Secretary would be obligated to submit an annual report to Congress, reporting on the status of such agreements between the states and HHS/HCFA, including the state's original ICF/MR expenditure projections, any revisions in such projections occurring during the year, the

reasons for such revisions, and any systemic steps that should be taken to control future increases in ICF/MR operating costs.

Advantages. This approach would create a logical planning and implementation framework within which the federal government and individual states could negotiate all of the ramifications of systemwide changes that are occurring — and presumably would continue to occur — in the delivery of Medicaid-financed services to persons with developmental disabilities. At present, states complain that they are subject to being whipsawed by the unpredictable results of ICF/MR surveys, which can undermine the best laid plans to expand and enhance community-based services. By forcing long range resource commitments involving community expansion and ICF/MR improvements into the same decisionmaking framework, both HCFA and the subject state would be required to weigh the interrelated, systemwide consequences of any plans.

States would retain authority to claim full federal financial participation in the cost of operating ICF/MRs, regardless of their bed capacity - a fact that should answer a principal concern of critics of the Chafee/Florio freeze proposal. Yet, at the same time, both the federal government and the states would have stronger incentives to control the growth in ICF/MR expenditures ~ the states because their plans to expand community-based services would hinge, to a large extent, on their capacity to maintain ICF/MR expenditures on a predictable course; and the federal government because the Secretary would be required to justify all extraordinary increases in ICF/MR outlays in an annual report to Congress. [N.B., Under current policy, increases in ICF/MR costs that occur as a result of the correction of deficiencies resulting from federal or state surveys are indistinguishable from other state claims and, furthermore, usually are not reflected in federal-state fiscal reports until at least a year (and often 2-3 years) after the fact.]

Although this approach is designed to be used in conjunction with a state's decision to cover optional home and community-based services under its state Medicaid plan, it is flexible enough that it could be used with other coverage options, including a Section 1915(d)-like waiver or a modified Section 1915(c) waiver.

Disadvantages. This approach is similar, in many ways, to the existing ICF/MR reduction/correction plan option under Section 1922 of the Act. Therefore, it is important

Under Section 1922, when the decertification of an ICF/MR is threatened, a state may propose a three-year phase-down plan that will: (a) result in a reduction of the number of persons served in the facility; and, (b) at the end of the three-year period assure that the facility complies with all regulations. Conceived of as a middle-road between the disruption that stems from immediate decertification and the oftentimes extended period of time needed to bring (continued, following page)

to point out that, as of December, 1988, HCFA/HHS had yet to formally approve a single Section 1922 reduction/correction plan; furthermore, even though the 100th Congress modified this statutory authority before adjourning, it seems unrealistic to expect that Section 1922 will ever serve as more than a last ditch response to imminent decertification. Under the circumstances, it would be overly-optimistic to assume that a similar discretionary authority would yield significantly better results as a mechanism for resolving the competing interests that must be balanced in any long term, systemwide reconfiguration of services.

Opposition to such a proposal can be expected from institutional parent groups and unions, who are likely to view it as another device to further the states' deinstitutionalization policies. While it might be possible to alleviate some of these concerns by building into the proposal provisions for public review and employee protections similar to those already mandated under Section 1922, the more conditions that are attached to the approval process, the harder it will be for states to take advantage of the opportunities offered by such a discretionary authority.

Furthermore, even if one were to accept the underlying premises, it seems likely that the proposed approach would serve as a relatively weak restraint on the growth in ICF/MR costs. Even under the best of circumstances, it is extraordinarily difficult to predict the way in which the pressures to perform within any given ICF/MR influences the capacity of facility managers to maintain compliance with federal operating standards, while at the same time remaining within pre-established expenditure levels. The recently published revision in HCFA's ICF/MR standards, with all the uncertainties they pose regarding future budgetary impacts, makes this task doubly difficult. In view of these realities, states might decide that the course of least resistance when faced with the prospect of having a facility decertified is to escalate ICF/MR expenditures.

Finally, from the point of view of professional and citizen advocates of community-based services, this approach, no doubt, would be considered a poor substitute for a mandate to reduce the capacity of large ICF/MR facilities, or, at least, to freeze the level of Medicaid

(continued from preceding page) a facility into compliance, Section 1922 is roughly similar in its aims to the waivers that were extended to states to come into compliance with the 1974 ICF/MR regulations. The course of facility census reduction was advocated as a more economical approach to securing ultimate compliance than a state's throwing new resources at a non-compliant facility. Present HCFA regulations, however, disqualify deficiencies in "active treatment" services as a basis for the submission of a Section 1922 request. In addition, present regulations require that a state develop an extremely comprehensive plan within a very short period of time in order to utilize the Section 1922 provisions.

funding of such facilities. Also, to the extent that savings in institutional Medicaid spending is seen as a prerequisite to convincing Congress of the wisdom of adding home and community-based services as a coverage under Title XIX, an optional approach to holding down ICF/MR expenditures is likely to yield far less savings than the mandatory Chafee/Florio freeze proposal.

Impose a statutory moratorium on enforcing the active treatment requirements of the June 3, 1988 revised rules, pending the outcome of a mandated review of HCFA's current regulatory definition of active treatment (including associated interpretive guidelines) as well as the agency's methodology for assessing compliance with this regulatory condition of participation. Under this approach, the Secretary would be required to establish a national commission, consisting of a representative group of experts in delivering ICF/MR services to persons with developmental disabilities, to conduct a study and formulate recommendations to Congress and the Secretary on steps that should be taken to assure a more consistent application of active treatment regulatory standards, from facility to facility and state to state. The Secretary, in turn, should be required to publish the findings and recommendations of this study as a Federal Register notice and solicit public comments. Once these comments were received and analyzed, the Secretary should be obligated to publish, by a date specified in law, any necessary modifications in applicable regulations and guidelines to implement a revised procedure for assessing compliance with the active treatment condition of participation. During the period of this statutory moratorium, the former regulatory requirements governing active treatment should be used as the basis for assessing compliance.

Advantages. A temporary moratorium on enforcement of the new active treatment requirements would remove one of the major causative factors that lead to uncertainties surrounding future ICF/MR expenditure levels. As such, it should make it easier for states to maintain control of ICF/MR spending levels over time and, thus, to pursue their systemic reconfiguration goals.

In addition, the appointment of a national commission would place contentious questions surrounding the operational definition of active treatment and methods of assessing compliance with related federal regulatory requirements into a forum where they could be resolved and new national consensus struck. Under present law, it can be argued, that such problems will continue to fester until they result in a level of federal-state and state-provider conflict that will be more difficult to resolve. A similar technique was used with considerable success in 1984-86, when nursing home advocates, Congress, the states and the Reagan Administration were at loggerheads over the best approach to regulating Medicare and Medicaid-certified nursing homes.

Finally, the approach itself is straight-forward and easy to explain. As such, it should be simpler to rally state and provider support behind it — a fact which should improve the prospects of enactment.

Disadvantages. This proposal is certain to be viewed as a dilatory tactic in many quarters - i.e., just another

technique to avoid accountability for substandard performance. HCFA officials can be expected to argue that an extraordinary effort was made to involve consumer, provider and professional interest groups during the six-year process of developing the revised ICF/MR standards and, therefore, it is fair to say that the new active treatment requirements reflect current state-of-the-art thinking in the field of developmental disabilities. They also will contend that extensive efforts have been made to make the revised ICF/MR survey process, as it relates to a facility's compliance with the active treatment standards, as objective as possible. These arguments, no doubt, will have a telling impact on many professionals and consumers, as well as some service providers, who can be expected to oppose such a statutory moratorium.

If one were to conclude that a statutory moratorium is desirable and could be enacted despite such opposition, the states could not necessarily expect that the vulnerability of ICF/MRs to decertification actions on the grounds of failing to provide active treatment would be removed. Indeed, HCFA was citing facilities for active treatment deficiencies long before the issuance of final, revised standards, and could be expected to continue this policy even if a statutory moratorium were enacted by Congress.

Support the enactment of selected statutory clarifications in federal ICF/MR policies, which are aimed at establishing a clearer framework for developing HHS/HCFA regulations governing the operation of such facilities. This approach would attempt to strike a balance between a general delegation of regulatory authority to the Secretary (as under current law) and the addition of detailed, highly prescriptive standards to Title XIX of the Social Security Act (as proposed in the Waxman bill). Although the specifics of such a proposal would have to be developed, the underlying notion is that a separation would be made between basic policy benchmarks (that would be incorporated in law) and the operational manifestations of such policies (that would be contained in HHS/HCFA regulations). The expectation is that basic policies would be relatively immutable (i.e., unlikely to require periodic updating), while the contents of the regulations probably would have to be revised from time to time to offer clearer guidance to operators of ICF/MR facilities.

Advantages. This approach might placate critics of the Chafee/Florio bill, who feel that, besides its other defects, S.1673/H.R.3454 would tilt Medicaid policy too far in the direction of community-based services. Regardless of the accuracy of this perception, there may be merit in promoting a piece of legislation that makes a conscious attempt to clarify federal law as it applies to ICF/MRs. It seems clear that Mr. Waxman's bill, despite one's views regarding its merits as introduced, is an attempt to satisfy the various competing forces in the debate over DD Medicaid reform legislation. Given this fact, it can be argued that it simply will not be possible to enact DD Medicaid reform legislation unless it contains improved assurances that high quality standards will be maintained in ICF/MRs. If so, the challenge is to draft a proposal that deals

with any real or perceived defects in Title II of Mr. Waxman's bill.

Disadvantages. To begin with, it would be an extremely difficult task to redraft Title II of H.R.5233, since no doubt it would be necessary to justify every change that is proposed because Waxman's staff begins with a bias toward maintaining as much parallelism as possible between Medicaid statutory provisions governing nursing facilities and ICF/MRs. Furthermore, any attempt to make basic changes in Title II of the bill probably would be opposed by institutional parent groups and organized labor, who would view such modifications as an effort to water down the contents of the bill as introduced.

Putting aside the question of opposition to changes in Title II of the Waxman bill, it is not clear that it would be possible to achieve consensus on what constitutes the basic requirements that should appear in federal law vs. policies that should be spelled out in administrative regulations. At best, the process of negotiating such an agreement would be long and tortuous.

Even if an agreement could be reached, the direct benefits of including additional provisions governing the operation of ICF/MRs in federal law are difficult to perceive. HCFA regulations already spell out, at great length, the conditions under which a facility may be certified as an ICF/MR provider and the methods and procedures to be used in making such certification decisions. These regulatory provisions have the effect of law. Why then, one might ask, is it necessary to enact further statutory provisions on this subject? Would it not be easier to seek modifications in those particular aspects of the federal regulations that are causing problems?

4. Summary

Despite, then, the frustrations spawned by present federal policies governing the ICF/MR program, it is far from clear that a consensus could be formed to undertake major changes in the structure and purposes of this program. At the same time, however, failure to reconcile ICF/MR policies with the philosophical directions advanced for community services by Medicaid reform advocates leads to a clear danger that the present bifurcation in state service delivery systems will persist.

F. Appropriate Placement of Persons with Developmental Disabilities

Related to issues in eligibility and ICF/MR policies is the issue raised by Representative Waxman in H.R.5233: namely, should federal policies be established that would directly regulate the admission of persons with developmental disabilities to ICF/MRs? This issue is sufficiently important to be considered on its own merits.

1. Current Law

Under existing Medicaid law, states are given broad latitude in establishing admission and continued stay criteria applicable to persons served in Title XIX-certified intermediate care facilities for the mentally retarded (ICF/MRs). To be found eligible for ICF/MR services, an individual must: (a) meet the state's Medicaid income/resource eligibility standards; (b) be determined to be mentally

retarded or have a condition related to mental retardation; and (c) be found to be in need of long term care services provided in an institutional setting. In defining "mentally retarded" and "persons with related conditions", current HCFA regulations and guidelines specify only in general terms the types of persons who may be served in ICF/MRs. The task of establishing operational criteria governing admission to, and continued stays in, ICF/MRs, therefore, is left largely to the discretion of each participating state.

2. Unresolved Issues

One question that is certain to arise in the context of Congressional consideration of Medicaid reform legislation affecting persons with developmental disabilities is whether federal law should contain a more specific set of parameters governing admissibility to ICF/MRs. Indeed, Section 301 of the Waxman bill poses this issue by recommending the establishment of a preadmission screening and resident review program applicable to ICF/MRs that parallels the nursing home reform provisions of Section 1919(e)(7) of the Act, as added by the 1987 reconciliation legislation. The most basic question that needs to be answered is: should there be national standards of eligibility governing admission to, and continued stays in, ICF/MR facilities; and, if so, should the Secretary of Health and Human Services be empowered to establish such standards? In addition, assuming that national standards are developed, one must decide whether the preadmission screening/resident review requirements presently applicable to Medicaid-certified nursing facilities constitutes an appropriate legislative model for establishing such standards. Furthermore, what relationship should such standards, if enacted, have to eligibility for other Medicaid-reimbursable services?

From the states' perspective, the major drawback of Section 301 of the Waxman bill is that it would grant the Secretary unlimited power to tighten ICF/MR eligibility criteria and, thereby, restrict the number and types of persons eligible to receive such services. At a time when the Executive Branch (i.e. OMB) places highest priority on containing the growth in federal Medicaid outlays, such an authority could result in an effort by OMB to modulate ICF/MR admission/continued stay criteria to fit the Administration's fiscal goals. It is important to note that such a policy would not only restrict participation in ICF/MR services, it also would Emit participation in HCB waiver programs as well as "community habilitation services" (as proposed under the Waxman bill), since eligibility for the latter services are directly tied to an individual's need for ICF/MR level of care.

Finally, there are a number of pitfalls to patterning ICF/MR preadmission screening and resident review requirements after the provisions of the 1987 nursing home reform legislation. As originally introduced, Section 301 of H.R. 5233, for example, would direct the states to determine (and redetermine annually thereafter) whether each current ICF/MR resident needs active treatment and arrange to transfer those who do to a facility in which they can receive such services. But, the legislation constitutes something of a non sequitur since, by definition, the only setting in which active treatment can be provided is an ICF/MR!

3. Proposed Solutions

There are several possible alternative approaches to addressing the question of national ICF/MR admission criteria, including the following:

- a. **Oppose the promulgation of national ICF/MR admission/continued stay criteria.** This option would leave in place existing law, thus preserving state discretion in this area of ICF/MR policy.

Advantages. Current law implicitly recognizes that:

the views of the field regarding the types of persons who require services that can be furnished most effectively in an ICF/MR have changed considerably over recent years and are likely to continue to change in the years ahead;

there remains substantial disagreement in the field of developmental disabilities concerning the profile of service needs that should equate with admissibility to, or continued residence in, an ICF/MR;

the states are at different stages in the development of community service networks and, consequently, vary significantly with regard to the number and types of persons served in ICF/MRs.

All of the factors outlined above argue persuasively for the retention of a substantial degree of state flexibility in establishing ICF/MR admission/continued stay criteria. To begin with, it is hard to conceive how a national criteria, based on functional indicators, could be developed without causing major dislocations in many states. For example, there undoubtedly would be a considerable number of existing ICF/MR residents who might not be considered appropriate candidates for admission under current practices, as they might be articulated in a set of national criteria, but, nonetheless, need a structured living and programming environment that either may not be available or may not be deemed appropriate given the current affective needs of the particular individual.

Furthermore, in view of the current dynamic situation facing the field, it is not clear that the promulgation of national criteria is either desirable or feasible. Even if one were to assume that a national consensus could be achieved (a highly dubious assumption at best), the likelihood is that any uniform national criteria soon would become obsolete as concepts of appropriate programming continued to evolve.

Disadvantages. The existing interstate variations in policies governing ICF/MR admissions poses obvious national policy problems, especially within the context of a piece of legislation that is designed to "clean up" Medicaid law as it impacts on the operation of such facilities. Regardless of views concerning the need to retain state flexibility in this area of Medicaid policy, it can be argued that adamant opposition to changes in existing law would not be well advised if, as appears likely, Congress is committed to modifying current policy in some

In addition, accepting the proposition that the lack of a coherent means of rationalizing Medicaid financing for ICF/MRs and community-based services represents a fundamental barrier to true reform, it could be argued that a properly structured process for developing ICF/MR

admission/continued stay criteria may contribute to the removal of such barriers and the forging of a new consensus within the developmental disabilities field.

- b. Direct the Secretary to contract with a disinterested organization to sponsor an indepth study of ICF/MR admission policies and make recommendations to Congress and the Secretary of HHS. The organization selected to host this study would be directed to appoint a national study panel, the membership of which would be broadly representative of various segments of the developmental disabilities community that have a stake in the operations of ICF/MR facilities (e.g., consumer representatives, public and private providers, state agencies, unions, etc). The mission of the study panel would be to: (a) analyze the impact of current policies; and (b) make specific recommendations for improving existing laws, regulations and practices governing admission to, and continued stays in, ICF/MR-certified facilities. As noted earlier, this same basic approach was used successfully in 1984 to resolve the political impasse over the regulation of federally-assisted nursing homes.

Advantages. This approach would remove the question of ICF/MR admission criteria from the political arena and place it in a framework where it would be subject to intensive scrutiny and debate, which might lead to a resolution acceptable to all interested parties. In the absence of such an in-depth study, it seems highly unlikely that an acceptable middle ground can be found that is satisfactory to Congress, the states and HCFA/HHS.

Disadvantages. One of the major drawbacks of this approach is that it may be viewed as a dilatory tactic. Proposals to "study the issue" are often viewed with skepticism in Congress.

In addition, it is difficult to predict the types of recommendations that might emerge from a national study group. Given the complexity of the issues involved and the divergent views of key actors in the field, there is no assurance that the final recommendations of the study group would form the basis of an acceptable compromise.

- c. Require any state that covers ICF/MR services under its Title XIX plan, or after a statutorily specified date (say, for example, one year after the effective date of the legislation), to begin using valid and reliable instruments, approved by the Secretary, to assess the service needs of persons with mental retardation and related conditions who: (a) are applicants for admission to an ICF/MR; or (b) have resided in such a facility for at least 12 months since their most recent reassessment. Under this approach, participating states would be obligated to use a Secretarially-approved assessment instrument(s) as part of all preadmission reviews of applicants for placement in an ICF/MR. The completion of such a preadmission assessment would become a condition of federal financial participation.

Furthermore, state and federal ICF/MR survey teams would be required to assess the continuing need of the facility's residents for active treatment services. This initial assessment would be conducted as part of the regular survey/validation process, using the sample of clients selected in accordance with the methodology spelled out in HCFA guidelines. Where the number of inappropriately placed persons identified during this phase of the survey exceeded a threshold level established by the Secretary, the

survey team would be required to conduct a more indepth assessment of the service needs of the facility's residents. Following this secondary review, depending on the number of misplaced residents in proportion to the facility's total population, the single state Medicaid agency (or HCFA in the case of federal validation surveys) would be directed to either: (a) decertify the facility on the grounds that it no longer met the basic statutory conditions for participation in the Medicaid program; or (b) withdraw FFP on behalf of all residents found to be inappropriately placed.

Advantages. This approach would avoid assigning broad, undefined authority to the Secretary of HHS, while at the same time putting in place a mechanism for assuring that persons with developmental disabilities receive an appropriate range and intensity of services and are not retained in an ICF/MR when they could benefit from a less restrictive living/programming environment. In addition, the capacity of each state to tailor its annual assessment program to the unique aspects of its current circumstances vis-a-vis the evolution of ICF/MR services also would be preserved.

Not only would this approach provide a more effective and potentially less disruptive means of monitoring the appropriateness of ICF/MR placements, but it would help to fill the void that would be created by the proposed repeal of existing utilization review and inspection of care functions under Section 302 of H.R. 5233. By incorporating into the federal-state ICF/MR survey process an annual assessment of the continuing need of a facility's residents for ICF/MR level of care, many of the limitations inherent in the current, parallel process of IOC/UR reviews could be avoided. Furthermore, the requirement that, in conducting such level of care reviews, states use scientifically validated assessment instruments that have been approved by HHS/HCFA should add to the objectivity of the findings of such reviews.

- b. Disadvantages. As long as the states are able to exercise discretion in determining the appropriateness of ICF/MR placements, the basic objective of establishing a uniform national eligibility floor would be undermined. In other words, it could be argued that the goals of national uniformity and state flexibility are simply incompatible. Thus, to the extent that Congress' aim is to achieve a national standard of eligibility for admission to, and continued stays in, ICF/MR facilities, this proposed approach might prove to be unacceptable.

Until the passage of the "nursing home reform" provisions of OBRA-87, medical review and inspection of care were conceived as assuring an independent, periodic assessment of the appropriateness of Medicaid-financed long-term care placements. In OBRA-87, Congress decided to repeal these requirements (effective in 1990), based on findings that neither activity yielded the desired results. Representative Waxman's proposal to repeal such provisions governing ICF/MR placements is based on the perceived ineffectiveness of these activities. As a substitute, preadmission screening would be strengthened (principally through the proposed promulgation of national assessment criteria and assigning responsibility for such screening to an "independent" agency) and resident review activities integrated with facility survey protocols.

4. Summary

While it might be argued that it is a reasonable course of action for the federal government to assure that very costly ICF/MR services are only being furnished to the individuals for whom they are most appropriate, how such "targeting" might be achieved without causing major disruption is a complex issue.

G. Employee Protections

The question of whether changes in federal Title XIX policies ought to be linked, in some fashion or another, to their potential effects on public employees serving persons with developmental disabilities in state-run facilities has represented a bone of contention in recent debate concerning reformulating present Medicaid policies. While clearly standing apart from the more central subjects of this debate, the issues in this area must be reckoned with if policy change is to occur.

1. Current Policy

Federal "employee protection plans" were initially mandated under the Developmental Disabilities Assistance and Bill of Rights Act, when it was reauthorized in 1975 (P.L. 94-103). Specifically, Section 122(6)(B) of the Act stipulated that "the [state DD Council's] plan must provide for fair and equitable arrangements (as determined by the Secretary after consultation with the Secretary of Labor) to protect the interests of employees affected by actions under the plan to provide alternative community living arrangement services, including arrangements designed to preserve employee rights and benefits and to provide training and retraining of such employees where necessary and arrangements under which maximum efforts will be made to guarantee the employment of such employees."

This provision is still contained in the Act. However, since the federal developmental disabilities program provides extremely limited support for direct services, Section 122(6)(B) of the Act has had little practical effect on the delivery of community-based residential services.

Under current Medicaid law, as amended in 1986, any state that submits a Section 1922 ICF/MR reduction plan (see above) must provide the Secretary with assurances that the interests of affected facility employees will be adequately protected. More specifically, these protections must include provisions for training and retraining such employees where necessary, redeployment of facility staff to community settings, as well as maximum efforts to guarantee continuity of employment for all such individuals (Section 1922(c)(7) of the Social Security Act). Currently, HCFA regulations implementing Section 1922 preclude states from developing reduction plans that address active treatment deficiencies and, as a result, no such plans have been approved to date, even though the legislative authority has been on the statute books for over 2 1/2 years. However, an amendment contained in the 1988 tax corrections act (P.L. 100-647) explicitly permits states to submit ICF/MR correction/reduction plans that deal with active treatment deficiencies and, consequently, HCFA will have to revise its Section 1922 regulations. [N.B., As this report was being completed, a draft regulatory revision was under discussion within HCFA, for possible publication early in 1989.]

2. Unresolved Issues

The most critical question to be resolved is: under what circumstances, if any, should federal policies require the states to develop affirmative plans to protect the legitimate interests of public and private employees? A closely related question is: how should any new federal policy initiatives in this area intersect with existing collective bargaining agreements and current efforts to achieve parity between the wages and benefits of employees in the public vs. the private sector?

The fact that public employees of state-run facilities represent a political force that must be reckoned with elevates these issues to a high level of importance in attempting to change present policies to direct an increasing share of Medicaid dollars to the largely privately-operated community-based service delivery system.

3. Proposed Solutions

The potential approaches to addressing the issues of employee protections and staff continuity might be summarized as follows:

- a. Add provisions to Title XIX that would parallel the provisions contained in the DD Act, thereby requiring each participating state to outline "fair and equitable provisions" to protect the interests of public employees affected by the transfer of eligible individuals from state institutions to community-based facilities and programs that are recipients of Medicaid financial assistance. States would be obligated under this approach to make maximum efforts to provide such employees with jobs, including arrangements designed to preserve employee rights/benefits and, where necessary, to make available training and retraining opportunities. This is the approach used in the Chafee/Florio bill. The bill does not contain similar protections for employees of private facilities; however, each state would be required to outline in its implementation strategy procedures for assuring fair employment standards and equitable compensation was available to workers in private programs and facilities that offered Title XIX-reimbursable services to eligible individuals with severe disabilities.

Advantages. Employee protection provisions similar to those contained in the Chafee/Florio measure would: (a) enable states to continue to implement current arrangements to address the concerns of public employees who are affected by efforts to reduce the censuses of large facilities; and (b) allow each state to tailor its approach to employee protections in a way that is appropriate to the unique situation and conditions that exist in the state's institutional and community-based service system.

The evidence from the closure of public MR centers over the past few years suggests that it is possible to reduce a state's reliance on large congregate facilities without causing undue dislocations for the employees of such facilities, if a state implements a multifaceted strategy to assist employees to located alternative jobs and makes related adjustments in personnel policies. The relatively non-directive provisions of the Chafee/Florio bill would not automatically require a state to undertake costly initiatives that could be interpreted as an open-ended guarantee of employment for all affected workers.

Disadvantages. In general, unions representing employees of public ICF/MRs have expressed the view that the employee protection provisions of the Chafee/Florio bill are inadequate. Citing examples of poorly planned and hastily executed facility closures, they contend that, in the absence of explicit federal safeguards, employees of state-operated MR facilities will be subject to the loss of their jobs with little prior notice or assistance in finding suitable alternative forms of employment.

More importantly, public employees unions believe that the provisions of a bill that would offer states financial

incentives to expand home and community-based services and further reduce the populations of large publicly-operated residential facilities would work to the detriment of the employees in such facilities, regardless of the planning requirements imposed on the states — especially since most states have elected to emphasize the provision of community-based day and residential services through private vendor agencies, where staff salaries for comparable positions are typically considerably below state pay scales.

From a political standpoint, the views of public employees and the unions that represent them must be given credence; the unions are viewed, in many circles, as a force that must be reckoned with in the formulation of Medicaid reform legislation affecting persons with developmental disabilities.

Another potential disadvantage of the general language of the Chafee/Florio bill is that it offers little explicit guidance to states in implementing employee protection plans. Consequently, the contents of such plans could be the source of considerable friction. State DD councils, for example, have encountered a good deal of confusion in implementing the parallel provisions of the DD Act. Because of the vastly greater dollars involved, such problems could be expected to be magnified several fold if similar language were included in Title XIX.

- b. Require states to provide assurances that certain explicit job protections will be afforded to employees whose jobs may be affected by the coverage of community habilitation services under state Medicaid plans. This, in essence, is the approach used in the proposed Waxman bill. Section 501 of H.R. 5233 would require states that elect to cover "community habilitation services" or seek approval of an ICF/MR reduction plan to make specified arrangements to protect the interests of affected public or private employees, including: (a) preservation of their rights under existing collective bargaining agreements; (b) protections against a worsening of the circumstances of employment; (c) assurance of employment for facility employees at the same pay level and level of responsibility; (d) paid training and retraining to qualify for alternative employment opportunities in "community habilitation services"; and (e) a grievance procedure that meets certain minimum requirements.

Advantages. This approach would offer significant protections to employees of publicly-operated institutions. Although it would not give public employee unions everything they are seeking in federal legislation (e.g., a requirement that the states operate community day and residential services directly), the Waxman language would be acceptable to most unions and the employees they represent. Even if one feels such language is unnecessary or undesirable, it may prove to be an essential precondition to enacting legislation.

The mandatory retraining requirement in the Waxman bill also would provide greater assurance that professional and para-professional staff, with expertise and experience in serving individuals with severe disabilities, are afforded the opportunity to continue to serve such individuals once

they move from large, state-operated institutions to small community-based settings. The result could be better continuity of care for individuals with developmental disabilities as they are transitioned from an institutionally-based to a community-based service system. The higher pay generally associated with public sector jobs also may lead to reduced staff turnover and burnout in community-based programs.

Disadvantages. The chief disadvantage of the Waxman language is its potentially high cost and the possible dislocations it may cause in existing patterns of delivering community-based services in many states. Although states are beginning to address the disparity in wages and benefits between state and private sector employees, there remains much work to be done. States that have attempted to narrow the gap have found it to be an expensive undertaking. To the extent that more explicit job protections resulted in expanded public operation of community facilities/programs, one would have to anticipate an increase in the total operating costs of such programs as well as a concomitant reduction in the rate of program expansion.

Another concern is that the Waxman proposal, as currently drafted, does not specify the circumstances under which the applicable employee protections would be triggered. There is no proven cause and effect relationship between the provision of Medicaid-reimbursable community services and threats to the job security of present employees. It can be argued that employee protections should not be blanket safeguards, but rather tied directly to the events which actually threaten the job security of facility employees, such as the phase-down or closure of large, publicly-operated facilities.

Second, the protections offered in the Waxman bill would apply equally to private and public employees. When a state is the employer, it can take steps to locate alternative positions for public servants who are displaced by the closure or phase-down of a facility. On the other hand, a state often is not in the same position with regard to employees of private facilities.

Section 501 of the Waxman bill would obligate states to assure that employee rights are preserved under existing collective bargaining agreements and through current certified representatives. As noted earlier, experience with the closure of mental retardation facilities underscores the importance of a multidimensional plan if the interests of existing employees are to receive maximum protection. The importance of state flexibility in developing such a plan cannot be overemphasized. Certainly, if state managers were limited to making transfers within the same collective bargaining unit, the alternative job options available might be severely restricted.

Additionally, the Waxman bill would require a state to establish specific grievance procedures for affected employees. While this provision seems reasonable, it could be argued that states with comparable grievance procedures under existing collective bargaining agreements should not be obligated to establish distinct procedures that are applicable only to employees covered by the provisions of the Waxman proposal.

Offer states incentives to provide community-based services directly to individuals with developmental disabilities. This alternative is a variation on the provisions of the Waxman bill. States, for example, might receive a differentially higher matching rate for publicly-operated facilities/programs under specified circumstances. According to the American Federation of State, County and Municipal Employees, fourteen states have developed state-operated community-based facilities or services. Four of these states (Connecticut, New York, Rhode Island and South Carolina) operate a rather extensive network of community services.

Advantages. If used in combination with the proposal outlined above, the development of state-operated community services would address the concerns of the unions which represent employees of public facilities. The necessary pool of experienced direct care workers is more likely to be retained under this approach. High rates of •, employee turnover, due to low wages and benefits, should be reduced, since workers would be better compensated and rewarded for longevity of service. Any short term increase in operating costs that might result from expanded public operation, it could be argued, would be more than offset by reduced staff turnover and burnout, combined with an inevitable narrowing of the personnel compensation gap between the public and private sectors.

Disadvantages. As noted above, the cost of a state-operated community services system could be quite high, at least in the near term, and would likely limit the capacity of states to respond to the growing waiting list for adult services. In addition, direct public operation of community-based services may inhibit innovation and creativity in the development and delivery of services, by imposing a standardized, bureaucratic set of rules on all public service providers. Such a development would run counter to efforts currently underway in a number of states to foster innovation at the grassroots level.

Finally, the inequities in working conditions, wages and benefits that currently exists between the public and private sectors could become even more pronounced. This would exacerbate the existing problems of finding and retaining qualified, experienced and dedicated workers in private sector provider agencies. For example, Connecticut officials report that community workers view the private sector as a training ground to develop experience in furnishing services to individuals with developmental disabilities; as soon as they have obtained the necessary experience, they move on to the state-operated group home system, where they perform essentially the same duties but receive significantly

increased pay and benefits, in addition to obtaining the protections afforded by union membership.

4. Summary

There is no doubt that the interjection of the strong interests of public employees into the debate concerning reformulating existing Title XIX policies piles additional complexities onto the question of how best to provide for a planful transition to broader use of Medicaid dollars in the community.

H. Paying for Services

Perhaps due to the technical nature of issues in rate setting and reimbursement, neither area has been regarded as a linchpin in efforts to reformulate current Medicaid policies. Yet, reform proposals touch on these areas; in addition, there is no doubt that whether and how current policies might be changed will have a substantial impact on the provision of services to persons with developmental disabilities.

1. Current Policies

Present federal Medicaid policies governing rate setting and reimbursement for services have the following major features:

With regard to ICF/MR services, state rate setting policies must conform to the so-called "Boren Amendment" (Section 1902(a)(13) of the Social Security Act), which requires that the payments made by states to institutional providers be "reasonable and adequate to meet the costs which must be incurred by efficiently and economically operated facilities in order to provide care and services in conformity with applicable State and Federal laws, regulations, and quality and safety standards...". Also, a state's policies must conform to certain generic cost finding principles governing Medicaid payments. Within this framework, states have broad discretion to select specific rate setting and reimbursement methodologies.

- Also with regard to ICF/MR services, federal policies permit essentially all costs of services furnished by a facility to be recovered via Medicaid reimbursement.

In July 1987, HCFA reasserted its long-standing administrative policy that payments to institutional vendors comport with the "Medicare upper limit" test. In the course of adopting new regulations in this area, HCFA singled out the ICF/MR program

While this report is not the appropriate means to spell out the details of this complex test, it represents an effort by HCFA to impose payment restrictions employed in the federally-administered Medicare program on Medicaid long-term care services. In particular, state payments to Medicaid long-term care providers are to be tested against the level of payment that would ensue if certain Medicare rate determination principles were applied. If a state's payments fail this test, then presumably the difference between the amounts allowable under application of Medicare principles could be disallowed. HCFA has contended that its authority to employ Medicare principles (even for ICF/MR services, which are not a benefit of Title XVIII) is reflective of Congressional intent and Section 1902(a)(30) of the Social Security Act which instructs the Secretary to "provide such methods and procedures relating to...the payment for care and services available under the [state] plan...as may be necessary to...assure that payments are consistent with efficiency, economy, and quality of care."

for special scrutiny and also mandated that payments to state-operated ICF/MRs be examined separately to determine whether they comply with the Medicare upper-limit test. This test specifies that increases in vendor payments must be in line with general Medicare inflation factors and, furthermore, it restricts payments when a facility's costs exceed norms for similar facilities.- In the HCB waiver program, states have broad discretion in establishing payment levels and selecting rate determination methodologies. Payments for HCB waiver services must be consistent with generic federal requirements concerning the allowability of Medicaid costs.

Also, in the HCB waiver program, the costs of "room and board" furnished to recipients of residential services, as well as the cost of services that may be furnished to waiver recipients but not specifically covered under the state's HCB waiver program, are not eligible for Medicaid reimbursement.

Finally, despite the discretion afforded states in choosing particular approaches to rate setting and reimbursement under Medicaid, present policies pose substantial obstacles to a state's employing innovative funding strategies in paying for community services. Moreover, more than a few states have had significant difficulties in attempting to reconcile Medicaid payment policies with strategies used to fund non-Medicaid services.

In this area of policy then, current federal laws and regulations allow a state considerable discretion in determining the level of payments for specified types of services. At the same time, there are noticeable differences between the types of costs considered reimbursable under the HCB waiver and ICF/MR programs.

Unresolved Issues

The principal unresolved Medicaid rate setting and reimbursement issues can be summarized as follows:

HCFA's imposition of the Medicare upper limit test, as it impacts on payments for ICF/MR services, potentially poses a very serious impediment to recovering legitimate and necessary ICF/MR costs through the Medicaid program. This problem cuts across all types of ICF/MR facilities, whether large, small, privately or publicly operated.

In addition, HCFA's plan to apply special tests to payments for services furnished by state-operated ICF/MRs could raise considerable problems for the states. Faced with rapidly rising costs in such facilities, states may find that federal payments are not keeping pace.

The HCB waiver program's "room and board" exclusion is a potential problem. Under certain circumstances, this exclusion makes it difficult to access federal dollars to meet the capital costs of community residential facilities. In this regard, there may be strong financial incentives to pursue residential development through the ICF/MR program, where such costs are fully compensated, even though the waiver might offer a more compatible environment in which to accomplish the program goals of many persons who require structured out-of-home living arrangements.

In some states, synchronizing Medicaid payment requirements with more general strategies regarding the funding of community-based services has led to substantial problems in developing a unified approach to managing the resources available to meet the needs of persons with developmental disabilities. As a consequence, payment strategies have become bifurcated. This problem is frequently noted as an outgrowth of a state's implementation of an HCB waiver program.

Finally, some have suggested that states have employed the discretion afforded by the Boren Amendment to depress rates paid to private agencies. It is argued that, unless checks and balances are incorporated into federal law, the ability of community-based agencies in many states to furnish adequate services will be severely compromised.

While these issues have received relatively little attention in the ongoing debate over Medicaid reform legislation, they nonetheless represent important dimensions of federal policies.

3. Proposed Solutions

Various proposals have been put forth to rectify particular problems surrounding Medicaid payments for specialized DD services. It seems fair to say, however, that none of these proposed solutions represents a comprehensive approach to forging consistent federal policies in this area. Among the steps that might be considered are:

- a. Prohibit HCFA from imposing the Medicare upper limit test on ICF/MR services and extend the Boren Amendment principles to all community-based services. H.R.5233 proposes (as Representative Waxman has in several past bills) to prohibit the Secretary from imposing the Medicare upper-limit test on ICF/MR services. The Chafee/Florio bill is silent on this issue. [N.B., Federal regulations imposing the test were finalized about the time work on the 1987 version of the Chafee/Florio bill was being completed.] In addition, both the Waxman and Chafee/Florio bills would extend the Boren Amendment provisions to cover all community-based services furnished under a state's Medicaid plan.

Advantages. Prohibiting the Secretary from imposing the Medicare upper-limit test would be of significant benefit to the states and to certified providers of ICF/MR services, particularly given the fact that increased federal oversight of ICF/MRs has destabilized program costs. Ultimately, the imposition of this test represents an additional constraint on a state's ability to manage systemwide financing of Medicaid services.

The extension of Boren Amendment principles to cover other services also can be viewed as advantageous to the states. In particular, the authority for a state to manage rate setting policies and practices would be affirmed by such language. In addition, the risk that state payments for such services might be artificially constrained at some future date through generic HCFA policies would be reduced if, as proposed in the Waxman bill, a separate statutory authority was created for establishing payment rates for community habilitation services.

Disadvantages. No disadvantages are associated with these proposals. However, it should be noted that the elimination of the Medicare upper-limit test has not been supported in the past by the Senate or the Reagan Administration. Consequently, successful removal of the upper-limit test ultimately may entail a compromise that assures that state rate setting policies result in equitable outcomes for both publicly and privately-operated facilities. Perceived inequality in this area has been advanced as a rationale for HCFA's July 1987 regulations.

In addition, one also should keep in mind that other interest groups are uncomfortable with the discretion afforded states under the Boren Amendment. These groups may lobby actively for further specifications in federal laws governing state management of payments to institutional and community vendor agencies (e.g., rates that assure adequate staff salaries). If such provisions were to be adopted, state Medicaid rate-setting and payment policies would be subject to greater federal scrutiny than is currently the case.

- b. Establish clearer statutory guidelines governing the types of services that are considered allowable for Medicaid reimbursement. The Waxman bill, for example, proposes the addition of a more explicit statutory definition of "room and board" costs that would apply to both HCB waiver services and optional community habilitation services covered under a state's Medicaid plan. This step was suggested by NASMRPD as a means of preventing HCFA from broadening the scope of costs associated with the provision of "room and board" and, hence, reducing reimbursement for community-based residential services.

Advantages. Given the recent tenor of HCFA's administration of the HCB waiver program, the adoption of a defensive posture that carefully defines allowable costs (or, just as importantly, allowable services) may be essential. Such a posture would take cognizance of the fact that a deficit-conscious Administration is likely to pursue policies aimed at reducing federal Medicaid outlays through administrative constricts. Certainly, this has been part of the history of the states' interactions with the outgoing Reagan Administration.

Disadvantages. The chief disadvantages in this area are: (a) the difficulty in crafting statutory provisions that will yield the desired outcomes; and, (b) the inherent problems in anticipating all the possible devices a hostile Administration might use to impede access to Medicaid funding of services for persons with disabilities.

- c. Establish a dear basis for employing Medicaid dollars to meet some or all of the housing costs of persons receiving community-based residential services. While exact circumstances vary from state-to-state, the HCB waiver program's exclusion of "room and board" costs from Medicaid reimbursement can pose significant problems for states that are interested in marshalling the resources-needed to develop community residences. At present, the ICF/MR program provides a much sounder footing for accessing Medicaid dollars to meet the capital costs of furnishing such services.

The Chafee/Florio bill attempts to address this issue by permitting states to recover Medicaid funding for any extraordinary costs that may be entailed in furnishing specialized (or specially adapted) community housing to persons with severe disabilities. At the same time, the bill's provisions in this area are somewhat ambiguous and do not directly address the problems associated with acquiring community residences in areas where housing costs are especially high. Others have suggested that extraordinary housing costs be treated in the same manner as they are treated under the ICF/MR program. Another alternative would be to permit the recovery of all housing-related costs through Medicaid payments that were not recoverable through the recipient's SSI benefit (including any state supplementation to federal SSI payments).

Advantages. While specific statutory provisions in this area may be difficult to develop, it seems clear that some even-handed means of regulating payments for food and shelter costs in both the ICF/MR program and other Medicaid-funded community residential programs needs to be established. To the extent that the present disparities in the treatment of capital costs under the ICF/MR and HCB waiver (or, successors to the waiver) programs are retained, they will pose a significant impediment to developing better integrated community housing options than are possible under the ICF/MR authority.

Disadvantages. The principal disadvantages to taking this step are: (a) Medicaid payments for community residential services are likely to be higher; and, (b) the adoption of such a policy may be perceived by some observers as a *de facto bias* in favor of providing out-of-home services.

Provide for some measure of state latitude in defining payment frameworks that depart from those traditionally employed in Medicaid's long-term care service delivery sector. Medicaid's "vendorization" model is distinctly at odds with how many states organize the flow of funds to purchase community-based services on behalf of persons with developmental disabilities. This is particularly the case when major responsibilities for the management of community-based services are delegated to regional, substate agencies. In such instances, Medicaid requirements that call for a direct contractual relationship to exist between a certified vendor and a state agency weaken the role of such substate agencies in carrying out their responsibilities. Alternative payment formulations might be defined which permit a state to assure compliance with certain key federal requirements while preserving the role of such substate agencies.

Advantages. To the extent that such alternative formulations can be put into place, the chances are better that the use of Medicaid funds can be better blended into a state's overall strategic approach to funding community services. As a consequence, bifurcation of services by funding stream would be minimized.

Disadvantages. Obviously, providing states with discretion in this arena would not readily satisfy Congressional or private provider agency objectives to assure that payment methods are reasonably standardized and provide basic protections to provider agencies. In

addition, it may be difficult to describe legislatively the scope of discretion to be afforded states or the benchmarks against which a state proposal to implement a new funding system would be evaluated.

Summary

Despite the potential influence that policies affecting payment methods may ultimately have on services furnished to persons with developmental disabilities, it is far from clear how many current issues in this area should be addressed in a reformulation of present federal policies.

I. Medicaid Administrative Responsibilities

Finally, the question arises of whether present federal policies ought to be changed in order to permit each state to better locate responsibility for the administration of Medicaid-reimbursable developmental disabilities services. Present policies have been characterized as foreshortening the ability of states to unify strategic system planning and management.

1. Current Policy

Under Section 1902 (a)(1) of the Social Security, a state is required to designate a single state agency to oversee administration of its Medicaid program. Although a state is free to develop its own unique methods of operating Medicaid services (as long as the single state agency continues to exercise overall accountability for the operation of the program), the Act provides states with no specific encouragement to develop administrative arrangements that create more effective bridges between the responsibilities of the state MR/DD agency under state law and the responsibilities of the single state Medicaid agency under federal law.

2. Unresolved Issues

Currently, one of the major barriers to the effective and efficient use of Medicaid dollars on behalf of persons with developmental disabilities in a large number of states is the fragmentation of fiscal and programmatic responsibilities among several agencies of state government. The distinctive missions, goals and operating procedures of state Medicaid agencies on the one hand and state MR/DD agencies on the other frequently act as a significant barrier to developing coherent and consistent plans for utilizing Medicaid dollars on behalf of eligible persons with developmental disabilities.

3. Proposed Solutions

The possible approaches to addressing the problems outlined above might be summarized as follows:

- a. Grant each state (i.e.~ the governor and/or legislature) authority under federal law to assign to the state MR/DD agency Title XIX administrative functions related to the provision of specialized services to persons with developmental disabilities and allow a state to claim FTP (at the administrative matching ratio) for the cost of any such services performed by a state MR/DD agency. This approach is identical to the provisions of Section 502 of the Waxman bill and similar to Section 1921 (i) of the Chafee bill.

Advantages. The states' experiences in administering Medicaid-financed services to persons with developmental disabilities strongly suggest that more effective management occurs where day-to-day financial control over Medicaid dollars is vested in the same state agency

that is programmatically responsible under state law. The proposed provisions of the Waxman and Chafee/Florio bills would promote such a consolidation of authority and responsibility and, therefore, should lead to more effective and responsive administration of program benefits on behalf of persons with developmental disabilities.

Disadvantages. Since the reassignment of Medicaid administrative responsibility would be a permissive authority, it could be argued that the proposed provision might be of little practical benefit to those states where the MR/DD agency has relatively weak political leverage. Ironically, it is in such states where interagency conflicts between the goals of the state MR/DD agency and the single state Medicaid agency are often the most pronounced.

- b. Mandate that certain specified responsibilities for managing Medicaid-reimbursable DD services be carried out by the state MR/DD agency, and that FFP be available to cover such administrative costs.

- * Advantages. This approach would assure that control over federal dollars and programmatic responsibility was consolidated within the state MR/DD agency in all states that participate in the Medicaid program - i.e., not only in those states where policymakers elect to employ such administrative arrangements. If one accepts the proposition that unified fiscal and program management represents a step in the right direction, then improved utilization of Medicaid dollars on behalf of persons with developmental disabilities should ensue.

Furthermore, the 1987 nursing home reform legislation (P.L. 100-203) provides at least some precedent for assigning specific Medicaid administrative responsibilities to the state MR/DD agency. Under this legislation, the state MR/DD agency is designated as the responsible state agent in determining whether residents of Medicaid-certified nursing facilities with developmental disabilities, as well as applicants for admission to such facilities, are in need of active treatment services and appropriately placed.

- Disadvantages. The mandatory assignment of Medicaid administrative responsibilities to the state MR/DD agency is likely to be opposed by state Medicaid directors and, possibly, the Governors, both of whom tend to be protective of a state's right to organize its Medicaid program as it sees fit.

In addition, some state MR/DD agencies may not be in a position to assume (or, indeed, may be unwilling to assume) broad new responsibilities for managing Medicaid dollars, particularly given the complexities entailed and the limited staff resources that may be available to them. Furthermore, the prospects of enacting a statutory provision of this type would be far less if particular administrative arrangements were mandated, rather than if a permissive authority (along the lines of the Waxman bill) were proposed.

- c. Amend 1902 (a) (1) of the Act to shift day-to-day responsibility for managing Medicaid funding of all long term care services to persons with developmental disabilities to the state's MR/DD agency, unless the governor or the legislature informs the Secretary of the state's decision to either maintain existing administrative arrangements or reorganize such responsibilities in another manner.

Advantages. This approach would significantly increase the odds that programmatic responsibility and day-to-day control of Medicaid expenditures would be consolidated in the same agency. Yet, at the same time, the state's elected policymakers would retain the ultimate authority to decide the most effective/efficient methods of organizing state government.

Disadvantages. It is not clear whether this alternative would be acceptable to state Medicaid program directors, state legislators and governors.

4. Summary

While it would be inappropriate to assert that how administration of Medicaid-reimbursable services is organized at the state level represents a highly visible issue in the debate concerning the reformulation of federal policies, it nonetheless has important ramifications in assuring a sound organizational structure within which to carry out more fundamental changes in policy.

J. Summary

The issues described above are enormously complex. They can be encapsulated in the following questions:

Who among the broad target population of persons with severe disabilities should receive Medicaid-assisted long term care services?

What types of services and supports should be funded on behalf of the identified target population through the Medicaid program?

To what extent can the fiscal ramifications of the proposed changes in federal Medicaid policies be accommodated within the federal budget, given the impact of the current deficit?

To what extent should Medicaid reform also encompass restructuring existing services? In other words, should the objective of legislative reform be to eventually replace the ICF/MR program or to authorize Medicaid-reimbursement for a range of home and community-based services that would complement the ICF/MR program?

How can Medicaid assistance be administered most effectively at the federal and state levels?

To what degree should federal policies preempt state policies with respect to serving persons with developmental disabilities?

The answers to these questions will have far-reaching consequences for the future of services to persons with developmental disabilities in the United States. In one respect or another, each of these areas must be addressed if a coherent, holistic approach to reformulating present Medicaid policies is to occur.

CHAPTER VI

CRITICAL ISSUES - DIFFICULT CHOICES

VI: CRITICAL ISSUES - DIFFICULT CHOICES

Each of the proposed approaches to resolving the current impasse over federal Medicaid policies as they affect persons with developmental disabilities is responsive – in one fashion or another — to the complaints levied by critics of the program. Although, as indicated in Chapters IV and V, each of the major proposals takes a different tact toward achieving desired modifications in current policies, they share the objective of attempting to create a broader, more reliable means of employing Medicaid dollars to meet the diverse needs of persons with developmental disabilities in the community.

At the same time, each proposal — in its own way — has potential drawbacks which impede the achievement of a consensus among the federal and state policymakers, state MR/DD agency officials, national consumer organizations, public employee unions, private-sector providers, parents, and others who hold a vital stake in the final outcomes of this debate. As with any other effort to change national policies, the final compromise version of the legislation is likely to represent a blending of the "bottomline" positions of each of these stakeholders. At present, however, it is unclear just how a compromise can be struck given the competing and overlapping objectives of the participants in the debate.

One of the major difficulties in reaching an acceptable compromise is that publicly-funded services to persons with developmental disabilities are highly reliant on Medicaid financing. As was noted in Chapter III, today nearly two out of every three public dollars expended on specialized services for persons with developmental disabilities passes through the Medicaid program. Thus, any significant change in federal Medicaid policies will have far-reaching consequences. Although there are significant defects in present federal Medicaid policies, the fact remains that entire service delivery systems are based on current Title XIX funding parameters. It is neither reasonable nor practical to predicate a Medicaid reform strategy on changing such policies overnight. The inevitable result would be substantial disruption in current service delivery systems. Hence, it is likely that any viable reform strategy will have to allow for a planful reconfiguration of current services over an extended period of time. The question that needs to be answered is not: how can present policies be completely displaced by a "new vision" of developmental disabilities services; rather, we need to ask: how can modified policies be devised to complement and enhance nationwide service delivery trends?

It also is necessary to face the reality that major Medicaid reform legislation in this area almost certainly will involve an uncomfortable and potentially divisive series of compromises among ideological/philosophical values, fiscal realities, and the present balance of state/federal program management authority. In the present decisionmaking climate in Washington, it seems unlikely that Congress will enact a new, broad-based entitlement to Medicaid-reimbursable services that each state is required to offer to all eligible persons. Furthermore, it is probably naive to expect that any liberalization in the use of federal Medicaid dollars to support community-based services on behalf of persons with developmental disabilities will not be accompanied by a more intrusive federal oversight role, eroding the historical role of states, local communities, and consumers in determining the scope and range of community-based services provided in each state.

A. Critical Issues/Difficult Choices

While it is difficult to single out the most critical choices that are likely to confront decisionmakers as they attempt to reformulate present federal Medicaid policies impacting on services to persons with developmental disabilities, there are a limited number of policy dimensions that seem to stand out. In the view of the present authors, the way in which the key dilemmas outlined below are resolved will determine to a large extent, the principle features of any Medicaid reform legislation that may be enacted.

1. To what extent should Medicaid reform be contingent on an acceleration in the rate of federal Title XIX outlays on behalf of persons with developmental disabilities?

The incoming Bush Administration and the 101st Congress face the unpleasant, but inescapable problem of reducing the federal budget deficit. At present, the projected difference between current budget projections and the Gramm-Rudman-Hollings deficit target for FY 1990 is \$40-50 billion. Many knowledgeable observers argue persuasively that this gap will widen due to rising interest rates (thus increasing payments on the enormous federal debt that has been accumulated over the past eight years) and a slow down in the rate of economic growth, now expected to occur in 1990. Thus, the Bush Administration's so-called "flexible freeze" plan for reducing the federal deficit without raising taxes may never be tested, since many economists would argue that the assumptions upon which it is based (a high rate of economic growth and low interest rates) are at odds with reality. Whether a solution to the deficit problem can be forged given the highly charged political milieu surrounding of the federal budget policy is unclear at present; but one can safely predict that:

efforts to reconcile the long-standing imbalance between federal expenditures and revenues will top the legislative agenda of the 101st Congress;

budgetary politics will have a profound influence on the contents of all substantive legislation considered by Congress over the next two years; and,

restraints on future federal outlays is almost certain to be a central feature of any deficit reduction plan that ultimately emerges.

Against the backdrop of the dilemmas posed by the federal deficit, it seems highly unlikely that any Medicaid reform legislation that entails significant increases in federal outlays for community services will be approved unless there is clear evidence that offsetting savings in institutional expenditures will be achieved. Under these circumstances, the fate of the Chafee/Florio approach to Medicaid reform would appear to be inextricably tied to a cap on federal outlays in larger Medicaid-certified facilities. In the absence of such a cap - a provision which is certain to be strongly opposed by several key interests groups as well as key House leaders - the Chafee/Florio bill is likely to be viewed as unaffordable under present conditions. An acceptable reform package then would have to be predicated on the adoption of policy changes that: (a) resulted in only modest increases in the rate of Medicaid spending for developmental disabilities services; or, (b) permitted states to expand community-based services by reprogramming current ICF/MR spending on a more reliable basis than is presently possible under the HCB waiver program.

Given existing budgetary restraints and the current Congressional method of calculating the fiscal ramifications of changes in federal Medicaid policy, the most likely shape that reform legislation might take is either a new optional community service state plan coverage or a Section 1915(d)-type waiver authority applicable to DD services (with appropriate modifications). Either alternative would offer a somewhat more secure basis for claiming Medicaid reimbursement for community services, but can hardly be expected to satisfy the pent-up demand and heightened expectations that have been raised during the five years of debate over Medicaid reform legislation. With state budgetary surpluses at their lowest point in twelve years, it should be noted that the ability of states to meet Medicaid matching requirements is limited. Thus, for many states, an expanded capacity to finance community DD services through their Medicaid programs may not result in immediate changes in state funding practices or priorities. Yet, any attempts to mandate increased expenditures for community-based services, without a concomitant increase in federal aid, are likely to be greeted by strong protests from state legislators and governors.

In short, present realities point in the direction of more modest, short range solutions to the problems posed by current Medicaid policies than many would prefer. It is by no means clear that supporters of more sweeping changes will lend their support to such incremental reforms, especially if the perceived outcome is to extinguish future opportunities for more basic legislative modifications in Medicaid policies. As a consequence, the underlying dilemma posed by the federal budget deficit could contribute to a continuation of the policy deadlock that has stymied past Medicaid reform efforts.

2. To what extent (if any) must present federal policies governing the ICF/MR program be reconceptualized as part of a broad-based Medicaid reform initiative?

In many important respects, the fiscal entanglements that have contributed to the stalemate over Medicaid reform legislation stem from the rising "threshold" of ICF/MR compliance imposed by HCFA. As it has become clearer and clearer that federal Medicaid policies must be changed to permit more diverse responses to the needs of persons with developmental disabilities, the states and provider agencies find themselves in a position where they are forced to increase their financial commitments to maintain the certification status of larger ICF/MR facilities, while at the same time attempting, in a severely constrained fiscal environment, to expand home and community-based services.

As was pointed out in Chapter in, the states' efforts to reduce their reliance on large ICF/MR facilities by continuing to downsize their own state-operated facilities have not led to a stabilization in nationwide spending on such facilities. Nor have private ICF/MR operators been immune to the financial effects of the rising threshold of compliance. The simple fact is that - regardless of the desire of state officials, private providers, or consumer organizations to reduce the role of larger ICF/MR-certified facilities ~ 144,000 persons reside in such facilities today and the likelihood (or even the advisability) of a major disinvestment in the ICF/MR program over the near-to-mid term is slim.

As a consequence, the cost of maintaining ICF/MR services increasingly is competing with state/local efforts to expand community DD services. In many states, the result is a sharp competition between the "haves" (those already enrolled in service programs) and the "have nots" (those awaiting services). Faced with this dilemma, states often have little choice but to maintain existing programs and forego the development of new service capacity. State officials know that the loss of the federal ICF/MR payments would create a negative multiplier effect that would result in systemwide funding reductions.

Thus, the price of Medicaid reform escalates for all parties as long as the costs of operating ICF/MRs (either public or private) rises. The question is whether it is appropriate, or even feasible, to address the problems posed by the continuing escalation in state/federal ICF/MR spending within the context of a broad-based Medicaid reform strategy? Many argue — with considerable evidence to support their point of view ~ that increases in the costs of ICF/MR services simply represents the price that must be paid for the states' past failure to conscientiously implement the program's basic regulatory requirements. Calling for reduced federal and state regulatory oversight of ICF/MR facilities will be viewed as tantamount to condoning inadequate programming and potentially dehumanizing conditions.

Yet, the fact remains that the rising cost of ICF/MR compliance has led the states to increase their investment in programs and facilities that many argue are overutilized and substantially out-of-step with current program values. If both federal and state resources are limited, an obvious (and potentially tragic) "zero-sum" game emerges as a result of the intensification of the ICF/MR compliance expectations. Scarce fiscal resources become concentrated on a narrower and narrower segment of the target population in need of services due to the nature and severity of their disabilities.

The 1987 version of the Chafee/Florio legislation would not alter ICF/MR regulatory requirements; indeed, it addresses the ICF/MR program in only one essential way: capping payments to larger ICF/MR facilities. In other words, states would bear the burden of all increases in the costs of operating larger ICF/MR facilities. While the effect of the proposed payment cap is certainly consistent with current programming trends, the implicit trade-off posed by the Chafee/Florio legislation — heightened ability to secure Medicaid coverage of community services in exchange for limited payments on behalf of residents of larger facilities -- is viewed by many states as the equivalent of a fiscal vise, given the likelihood that the cost of operating ICF/MRs will continue to increase at an uncontrolled rate.

The Waxman bill, on the other hand, would lock current ICF/MR program requirements in place by enacting them in statute and giving the Secretary of HHS additional enforcement tools, including civil penalties. The most predictable outcome of this step would be a continuation of an upward spiral in ICF/MR costs.

On balance, it seems clear that present ICF/MR spending trends, if they continue, will substantially erode the benefits of gaining a more reliable basis for rimming Medicaid dollars to support community-based services. Some have suggested that the basic tenets of the ICF/MR program need to be thoroughly re-examined and an "operational definition" of active treatment services developed, as part of an overall effort to assess the effectiveness of present federal requirements in promoting desired outcomes for ICF/MR residents (NASMRPD, 1988). Such a study has never been performed on the ICF/MR program.

However the thorny issues in this area might be addressed, it is important to recognize that Medicaid reform must be approached in a coherent, holistic manner. If one motivating factor for attempting to reformulate present Medicaid policies is to curtail the current imbalance in the types of Title XIX-reimbursable services that may be furnished to persons with developmental disabilities, one must recognize that the existing malalignment in resources is likely to continue unless a way is found to promote the expansion of home and community-based services while at the same time controlling the future growth in ICF/MR costs without sacrificing the quality of services rendered to facility residents.

3. How should eligibility to receive Medicaid-reimbursable services be altered as part of any legislation designed to address existing deficiencies in federal Title XIX policies?

In the minds of many people, the concept of "Medicaid reform" has become synonymous with accessing needed programs and services on behalf of persons with severe disabilities of all types. As emphasized in Chapter II, there is a very large (and, many would contend, growing) gap between the number of individuals who need specialized assistance and supportive services and the number who actually receive such Medicaid-financed services. The concept of "entitlement" under the Medicaid program is viewed as the key to removing existing barriers to retaining needed services.

The Chafee/Florio bill would create such an entitlement to at least a core set of mandatory services that each state would be required to furnish or face the prospect of losing their eligibility to participate in the Medicaid program. In contrast, the Waxman legislation would leave the decision concerning whether to cover such services to each state. Furthermore, both that bill and the ASPE/HHS proposal would narrow, at least potentially, the "window" of eligibility for ICF/MR services. The ASPE/HHS proposal goes one step further by arguing that the principal focus of all federally-assistance should be on persons who, on a prima facie basis, are likely to require life-long supports and assistance. These proposals suggest that the availability of Medicaid-reimbursable benefits somehow should be based on a criterion other than eligibility for the federal SSI program (as is proposed in the Chafee/Florio legislation).

Clearly, decisions regarding the extent and nature of the population eligible for services and whether such individuals are "entitled" to benefits is a fundamental consideration in drafting any Medicaid reform legislation. Present federal policies contain the so-called "need for institutionalization" test, a criterion that is increasingly at odds with contemporary values that undergird the delivery of developmental disabilities services. Access is further limited by restraints on the supply of ICF/MR beds or through the imposition of utilization caps in the HCB waiver program. These artifices combine to create the present gap between the number of persons currently receiving Medicaid-reimbursable services and the literally hundreds of thousands of persons with similar characteristics and needs who could benefit from ongoing supportive services. "Institutionalization" remains the least desirable outcome; indeed, a growing number of families are unwilling to accept that outcome. Yet present Medicaid policy defines the federal role in serving persons with developmental disabilities as assisting the states when persons are institutionalized (either directly or indirectly when eligibility for HCB waiver services is tested against the person's need for ICF/MR services).

In addition, if the "institutional bias" of the Medicaid program is to be removed or at least neutralized, present policies must be changed to create a "level playing field" where persons who live with their families will have access to Medicaid-reimbursable services. If support for family-based support services is to be a key element in a national strategy to encourage the provision of supportive services in the least intrusive manner and setting, then it will be necessary to provide a means to overcome present policy barriers to qualifying children and adults who live with their natural or adoptive families for Medicaid long term care eligibility. In order to do so, the historical linkage between receipt of public assistance (SSI or AFDC benefits) and Medicaid eligibility must be broken (see Chapter II for a discussion of parental/spousal deeming policies and the options currently available for circumventing such statutory restrictions on the Medicaid coverage of family-based services).

At the same time, reducing the gap between the present number of Medicaid beneficiaries with severe disabilities and the total number of individuals who legitimately could benefit from the provision of ongoing services and supports is likely to be an enormously expensive proposition. Arguably, the costs involved might be mitigated by restricting the types of services provided and/or the types of persons who are considered eligible for such services. The difficulty of reaching agreement on where such service eligibility/coverage lines could be drawn, however, should not be underestimated.

The challenges to be addressed in the area of service eligibility can be summarized by the following questions:

Should highly structured criteria for regulating access to Medicaid-reimbursable developmental disabilities long term care services be established in federal statute?

- Should such criteria be broad-based (e.g., requiring a person to meet SSI disability-related requirements) or designed to narrow the focus of persons entitled to receive federal assistance? How should such criteria be structured, if at all, to take into account a person's level of functioning?

Should each state be required to use uniform federal criteria of eligibility as a condition of the receipt of Medicaid payments for specialized services or be afforded the latitude to establish its own criteria?

Should each state be required to provide the same access to Medicaid-reimbursable community services to its individuals living with their own family as they afford to persons who have reached adulthood or live apart from their families?

Present Medicaid policies define a narrow "portal" of eligibility (i.e., the "need for institutionalization") that is objectionable for a variety of reasons. While many would agree with the need to change present policies, widening the portal of eligibility could have enormous fiscal consequences.

- 4, To what extent should federal policies dictate service standards applicable to the provision of Medicaid reimbursable services?

In any joint federal-state program, it is necessary to delineate the division of federal vs. state responsibility for establishing and enforcing program operating requirements and standards. The "inside the Beltway" perspective usually is that the acceptance by the states of federal financial support is contingent on the state's agreeing to conform to federally-defined standards and requirements. A quid pro quo exchange of increased federal assistance for increased federal rulemaking and oversight is a common trade-off in a wide variety of Congressional legislation.

The states, however, are very leery of such trade-offs, having been left in the back on many occasions in the past. Federal control of program standards and regulations results not only

in reduced state/local capacity to forge unique solutions to service delivery problems but also gives federal administrators enormous influence over the costs of furnishing services. The fact is that program standards and the costs of delivering services are inextricably intertwined. States need to look no further than their recent experiences with the ICF/MR program to find examples of how federal regulatory actions can lead to the loss of budgetary control.

Beyond the classical tension that exists between levels of government within the American federal system, however, many question the wisdom of centralization of program standard setting and regulation. In the field of developmental disabilities, it seems clear that the way in which the needs of individuals with severe disabilities are best met is undergoing a substantial transformation. Given the high level of dependency of states on Medicaid funding, the establishment of federal community service standards could create enormous barriers to future changes in service delivery methods. Tomorrow's potentially more effective approaches to existing limitations in the state-of-the-art could easily become the next Medicaid reform targets. In addition, it also is clear that effective quality assurance programs are multidimensional in character and include elements (such as consumer satisfaction surveys) that are inconsistent with the usual "policeman" role played by federal regulators.

Despite the well-known shortcomings of federal policies that are premised on "one-size-fits-all" program models and regulatory frameworks, the current environment in Congress appears to favor a more intrusive federal role in the management of Medicaid-reimbursable services. The nursing home reform provisions of OBRA-87 offer a recent case in point where Congress literally wrote into law a highly-prescriptive set of program standards and enforcement mechanisms to regulate the provision of nursing facility services. Furthermore, some observers have suggested that, faced with a new era of austerity in federal spending, Congress generally is more likely to be inclined to pursue national domestic goals through an expansion in the federal government's regulatory role.

Any realistic assessment of the present environment suggests that Congress, in formulating amendments to existing Medicaid laws affecting services to persons with developmental disabilities, is likely to opt for increased federal involvement in setting and overseeing the enforcement of community service standards. The question is can an acceptable middle ground be found between the extremes of simply giving the states *carte blanche* authority to regulate Title XIX-reimbursable community services and creating a federal regulatory apparatus which dictates how services will be furnished in each and every community in the United States. The 1987 Chafee/Florio bill sought to identify such a middle ground by requiring a state to outline specific approaches to meeting requirements as part of its overall implementation prior to initiating mandated and optional community and family support services. This approach contrasts sharply with unilateral regulatory role that would be granted to the Secretary of HHS under the Waxman bill. Another potential solution that has been advanced is to delineate in the statute minimum federal requirements pertaining to such areas as client rights and health/safety but leave to the states the establishment and enforcement of other program standards.

The area of program regulation represents a potential stumbling block in reformulating Medicaid policies in a way that will be acceptable to a wide spectrum of interest groups. States, for example, will be very wary ~ given their recent experiences with the ICF/MR program - of any solution that accords the Secretary of HHS unilateral authority to establish and enforce program standards applicable to home and community-based services. Other interest groups, however, may view a stronger federal presence as an acceptable (or even desirable) trade-off for increased access to Medicaid-reimbursable services.

5. How should the respective roles of the federal government **and the** states be balanced to assure proper accountability in the provision of Medicaid-reimbursable services to persons with developmental disabilities?

The issues associated with quality assurance represent a particularly critical subset of a larger question concerning the locus of accountability for the management of Medicaid-reimbursable services. While the Medicaid program was created as a means of furnishing federal assistance to help states provide health services to low income individuals and their families, the program increasingly is perceived by federal policymakers (and, reactively, by their state counterparts) as a federally-defined program for which the states provide matching funds. The Medicaid program has grown to such dimensions in most states that a state has few, if any, realistic alternatives to continued participation; consequently, a state is forced to comply with new federal policy initiatives as a condition of ongoing receipt of federal dollars.

In the field of developmental disabilities — as perhaps in no other area of state-supported human services program — the services financed by the states vary widely from jurisdiction to jurisdiction. Beyond differences in the scope and range of services offered to persons with developmental disabilities, community service delivery systems are organized quite differently from state-to-state (Gettings, 1987). Some systems are state-administered while in others numerous responsibilities are delegated to local governments or special purpose non-profit community agencies. In nearly every state, policy development is the outgrowth of formal and informal interactions between the state administering agency, provider agencies, local government bodies, and consumer interest groups. In addition, public funding of services is a very dominant form of financing.

These community service delivery systems stand in sharp contrast to other health care service delivery systems that participate in the Medicaid program. In other segments of the health care field, services are purchased from an "industry" that is more independent, both in terms of its organisation and its dependence on public funding. Furthermore, while state Medicaid programs vary considerably, the provision and organization of the services furnished to eligible recipients is more standardized than is the case in the field of developmental disabilities.

One of the most critical unanswered questions associated with the restructuring of Medicaid policies as they affect services to persons with developmental disabilities lies in the extent to which the character of each state's community-based service delivery system should be preserved if Medicaid dollars become a more important factor in financing non-institutional services. In other words, should the states be encouraged to integrate Medicaid financing of DD services into their existing approaches to managing and financing community-based services or should the receipt of Title XIX dollars trigger a basic restructuring of service delivery that ultimately results in greater state-to-state uniformity?

As has been noted in earlier chapters, the extension of ICF/MR certification beyond state-run centers to privately-operated facilities has made it difficult for many states to maintain a unified structure of community-based service delivery. From the states' perspective, one of the major strengths of the HCB waiver program is the capability it affords a state to blend Medicaid financing into its general approach to the management of community-based services.

As the debate surrounding Medicaid reform legislation unfolds, it is important to keep in mind that the infusion of more Medicaid dollars into community-based services can result in unintended changes in the basic character of existing service delivery systems. In the absence of specific statutory provisions permitting a state to delegate key tasks to local entities, for example, the acceptance of Medicaid support can undermine the ability of local communities to play a decisive role in managing developmental disabilities services. The seeds of such problems can be observed in the HCB waiver program as well as the extension of other Medicaid benefits to persons with developmental disabilities.

While the issues in this area are inextricably tied to the degree of authority delegated to the Secretary of HHS to establish prescriptive, uniform standards governing the provision and administration of Medicaid-financed community services, they also involve other key considerations, including:

Will special provisions be incorporated in statute to permit a state to tailor the administration of Medicaid-reimbursable services for persons with developmental disabilities to its own statutes that, in some states, empower substate agencies to play a decisive administrative role? Lacking such special provisions, "generic" Medicaid policies may force states to establish direct contractual relationships with all community service providers and, thus, bypass substate agencies

Will the provision of Medicaid-reimbursable community services require a state to engage in an open planning process that solicits and encourages input from service providers, consumer organizations, and others with a "stake" in the provision of Medicaid-financed DD services. The Chafee/Florio legislation would require a state in preparing its "implementation strategy", to seek feedback on its plans, program standards, and quality assurance program and forward this document to the Secretary of HHS. These requirements of the Chafee/Florio bill are a significant departure from the framework of generic Medicaid policies, where the single state Medicaid agency plays a unilateral role in determining how Medicaid-financed services should be structured and administered.

- Will "generic" Medicaid policies be modified to grant the states an opportunity to coordinate the flow of Medicaid and non-Medicaid dollars into the community service delivery system? For example, in paying for community-based services, will a state be permitted to select reimbursement methods that vary from conventional Medicaid payment models or must it manage two or more disconnected funding streams? Again, the application of "generic" Medicaid policies in this arena would force many states to adopt payment methods that are significantly different than those presently employed for community-based services.

Finally, will Medicaid reform legislation permit a state to unify program administration within a single state agency? Lacking any special provisions to the contrary, "generic" Medicaid policies would assign responsibility for the administration of any new or expanded Title XIX benefits targeted to persons with developmental disabilities to the single state Medicaid agency. As a consequence, the locus of accountability would not be with the state MR/DD agency which, under the statutes of most states, is charged with overall management of both community-based and institutional services to persons with developmental disabilities. There seems little doubt that the bifurcation of program and management responsibilities weakens accountability and ultimately impedes the development of coherent policies governing the delivery of community services. Both the Chafee/Florio and Waxman bills would address this problem by allowing a state's governor or legislature to assign administrative responsibility to a state's MR/DD agency.

In this area, it is vital to keep in mind that a more predominant Medicaid's role in financing community-based services has implications that extend well beyond the particular services or groups of eligible individuals who are entitled to receive such services. Unless special consideration is given to issues such as the foregoing, an unintended byproduct of increased

A current example of this phenomenon can be found in HCFA's administrative requirements governing the coverage of optional targeted case management services, in accordance with Section 1915(g) of the Act. At least one state (Pennsylvania) thus far has been required to agree to enter into direct provider agreements with agencies furnishing such Medicaid-reimbursable services, rather permitting county MR/DD units to manage such contractual agreements, as is the established practice under existing state law/regulations.

reliance on Medicaid financing could be a significant change in the character of a state's service delivery system and the way in which client-centered goals are pursued. Generic Medicaid policies - if applied across the board within the developmental disabilities service delivery systems — can result in major system management changes that would substantially reduce the role of local communities in solving key service delivery problems.

While it would be possible to identify many other issues, those discussed above represent, in the view of the authors, the most significant challenges to the articulation of sounder statutory policies governing the use of Medicaid dollars to support community-based developmental disabilities services.

B. Prognosis

Gaining a consensus regarding the reformulation of present Medicaid policies affecting Americans with developmental disabilities has been and will continue to be a difficult, complex undertaking. Among the organizations that recognize the need for reform, serious disagreements have arisen in the past regarding the specific steps that should be taken. Even if a consensus could be reached among these organizations, other interest groups have been quite vocal in asserting their opposition to changes in current Medicaid policies or in demanding guarantees that their particular interests will not be adversely affected by any revised policies. In addition, any proposal that might trigger an increased rate of growth in federal outlays on behalf of persons with developmental disabilities is certain to face tough sledding in the present federal budgetary environment.

Under the circumstances, it seems reasonable to conclude that many of the difficult issues surrounding the reform of Medicaid statutes as they impact on Americans with developmental disabilities will not be resolved unless bridges can be built between the approximately \$6 billion in state/federal spending that is presently dedicated to supporting institutionally-based services and a newly conceived framework in which federal assistance would be made available on a reliable basis to purchase supportive community-based services on behalf of persons with developmental disabilities. The construction of such bridges toward enhanced community-based services while at the same time avoiding the need to allocate an excessive amount of dollars to a receding institutionally-based service delivery system probably will prove to be the most decisive factor in the debate regarding Medicaid reform. In addition, any satisfactory set of statutory reforms must avoid the dictation of uniform national service delivery models and regulation, in order to allow the states and local communities to build upon existing frameworks for administering community-based services on behalf of persons with severe disabilities. The provision of constructive, realistic transitional strategies that build upon the strengths of present developmental disabilities service delivery will be an essential ingredient in such reforms.

In 1989, the 101st Congress will take up the debate concerning the reformulation of present Medicaid policies. At this juncture, two key actions will occur after Congress convenes in January.

The Senate Finance Committee will meet to mark up a reintroduced version of Senator Chafee's legislation. "Mark up" is the step usually required during the committee stage of consideration to put a piece of legislation into shape for floor action. Near the end of the 100th Congress, the Finance Committee's Chairman, Senator Lloyd Bentsen (D - Texas), agreed to hold such a markup session on the reintroduced version of Senator Chafee's "Medicaid Home and Community Quality Services Act." The Senate also passed a "sense of the Senate" resolution expressing its intent to take up Senator Chafee's bill early in 1989.

In the House, Representative Waxman has expressed his intent to reintroduce a modified version of H.R. 5233 in the 101st Congress, potentially with the support of Representative Florio if the differences between the 1988 Waxman bill and the 1987 Chafee/Florio bill can be resolved. However, while the specifics are still under negotiation, it seems

clear that any bill introduced by Representative Waxman (whether or not Representative Florio joins him as a co-sponsor) will: (a) retain open-ended funding of ICF/MRs regardless of their size (i.e., it will not include a cap on FFP for larger ICF/MRs); (b) add extensive statutory requirements governing ICF/MR standards and their enforcement; (c) provide significant protections for employees whose jobs are affected by decisions to phase down or close large ICF/MRs; (d) add a new community service state plan coverage, in all likelihood as a state option; and (e) restrict eligibility for such "community habilitation services" to a target population that is considerably narrower than the 1987 Chafee/Florio bill. In the House, any additional Medicaid costs associated with Representative Waxman's bill must be anticipated in the first concurrent budget resolution for FY 1990. If Representative Waxman is successful in getting such new spending authority built into the FY 1990 Congressional budget resolution, he has indicated a willingness to mark up his bill in the Energy and Commerce Subcommittee on Health (which he chairs), in 1989 and, thus, clear the way for floor action by the full House of Representatives.

While reaching the markup stage of the legislative process in either the House or the Senate (or both) would represent significant progress toward the enactment of Medicaid reform legislation, there are several other major hurdles to a bill actually becoming law. For example, unless additional spending authority is included in the Congressional budget resolution for FY 1990, action on Medicaid reform legislation is effectively dead until the following year, at the earliest. Given the fact that at least \$30 billion, and perhaps as much as \$50 billion, will have to be trimmed from the FY 1990 current services budget in order to stay within the Gramm-Rudman-Hollings deficit target, all proposals for new spending are certain to be scrutinized very carefully, with many being either rejected or severely cut.

Furthermore, the information available thus far suggests that the Senate and the House of Representatives are likely to pursue quite different paths toward Medicaid reform. If, for example, the Senate should decide to pass legislation along the general lines of the 1987 Chafee bill (i.e., authorization of an expansive new coverage of community-based services to a broadly defined target population, coupled with a cap on Medicaid payments to larger ICF/MRs) and the House rejects a cap in favor of narrower expansion of community services, it is not clear at this point whether a joint conference committee could come up with a compromise acceptable to both chambers, especially given the strongly held views, both pro and con, on the merits of an institutional payment limitation. Yet, as indicated earlier, it seems inconceivable in the current fiscal environment that Congress would be willing to approve Medicaid funding of community-based services in the absence of offsetting savings in program outlays.

In addition, it is important to keep in mind that, while reformulating Medicaid policies as they affect persons with developmental disabilities is obviously an important national agenda item, it will have to compete for Congressional attention with other meritorious proposals to expand federal spending. For example, during the 100th Congress, a number of members of Congress introduced sweeping bills to overhaul the funding of long-term care services for elderly persons. The Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360) barely addressed this critical area of federal policy, even though many members of Congress view it far more important to the welfare of older Americans than the expansion in acute care coverage that was included in P.L. 100-360. Even the most modest version of long term care reform legislation for the elderly would entail tens of billions of dollars in additional federal outlays.

In terms of the Medicaid program, there is growing national concern that millions of low-income Americans do not have access to basic health care services. For example, Medicaid current provides health care coverage for less than one-half of all persons living in poverty (down from 63 percent in 1975). During the 1988 Presidential campaign, both major party candidates agreed that a major national initiative was needed to assist the estimated 37 million Americans who today have no health insurance coverage (up from 26 million in the

late 1970s). President-elect Bush indicated that the Medicaid program should play a role in meeting the needs of such individuals, a sentiment shared by many members of Congress.

Similarly, Congress is certain to be under pressure to improve child health services. Despite successful efforts during the past three sessions of Congress to expand Medicaid coverage of poor children, one out of every five children live in a family without regular health care coverage and the United States remains tied for last place in rate of infant mortality among twenty industrialized nations.

Given these and other competing issues, it is not clear where legislation to reform Medicaid policies affecting persons with developmental disabilities will rank on the priority list of the incoming Bush Administration and Congress. To the extent that such changes in federal policy might trigger additional domestic spending (as they almost certainly will), a major competition for very limited federal resources can be expected.

Also, it is important to keep in mind that resolving the federal deficit is likely to take center stage at the beginning of the 101st Congress and may, as it has over the past several years, consume the attention of Congress and the Administration throughout 1989. A federal budgetary deadlock almost certainly will affect the prospects of passage of any piece of legislation that may increase federal domestic outlays. As a consequence, while it seems relatively certain that Congress will take up the reformulation of Medicaid policies as they affect persons with developmental disabilities, it remains unclear whether major reform legislation will be enacted in 1989 or beyond.

C. Conclusion

Despite some hopeful signs on the horizon, the long-standing Congressional impasse over Medicaid reform legislation is proving to be a source of considerable frustration to the states, provider agencies, consumers, and other national organizations. Five years have passed since Senator Chafee introduced his first bill intended to change the basic parameters under which Medicaid dollars are used to support services to persons with severe disabilities. As we enter 1989, it is by no means clear that the 101st Congress will resolve the debate by enacting major reform legislation.

While there has been noteworthy progress in efforts to reconcile the divergent points of view of various groups interested in reformulating present Medicaid policies, many complex issues continue to evoke differing points of view when they are addressed in the context of specific legislative proposals. Attempts to resolve such issues in a coherent, holistic manner almost inevitably thrust the debate into the arena of federal budgetary policy and the establishment of a strong federal role in overseeing how the states employ Medicaid dollars. As a consequence, interest groups that are striving to reform present policies are confronted with broad-scale issues that challenge them to compromise key objectives in return for achieving some (but probably not all) of their goals with respect to Medicaid reform.

How such compromises ultimately will be achieved without substituting a new set of federal policies that impose new barriers to the future evolution of services to persons with developmental disabilities is a complex challenge. At the same time, experience with the ICF/MR program over the past seventeen years should have taught us that changes in federal policy can have monumental (and, often, unintended) outcomes. Regardless of how and when such compromises are reached, they will substantially influence the character of publicly-financed developmental disabilities services throughout the 1990s.

APPENDICES

APPENDIX A:

THE CHAFEE/FLORIO LEGISLATION

APPENDIX A:

THE CHAFEE/FLORIO LEGISLATION

A. Legislative History

Over the past five years, legislation drafted and introduced by Senator John Chafee (R - Rhode Island) has served as the focal point for Congressional consideration of potential changes in federal Medicaid policies affecting persons with severe disabilities. The major recent version of this legislation, the "Medicaid Home and Community Quality Services Act of 1987" (S. 1673/H.R.3454; introduced in the House by Representative James Florio (D - New Jersey)), served as Senator Chafee's vehicle to promote Medicaid reform for persons with severe disabilities during the 100th Congress.

The Chafee/Florio bill - introduced in the House and Senate in the fall of 1987 - carried forward many of the themes of earlier bills introduced by Senator Chafee (S. 2053, introduced in the 98th Congress; and S. 873, introduced in the 99th Congress); however, it contained important changes as well. In large part, these changes represented the efforts of a small working group made up of representatives of the National Association of State Mental Retardation Program Directors, Inc., the Association for Retarded Citizens/U.S., the United Cerebral Palsy Associations, The Association for Persons with Severe Handicaps, the National Association of Developmental Disabilities Councils, and the National Association of Protection and Advocacy Systems. The "Ad Hoc Discussion Group on Medicaid Reform Legislation" was formed in late 1986 to develop tentative specifications for legislation to be introduced by Senator Chafee during the 100th Congress. The objective of this working group was to put together a bill that would address the basic objections raised with respect to Senator Chafee's earlier bills as well as to fashion a piece of legislation to which a variety of national organizations could lend their support.

After considerable give and take, a broader subcommittee of the Consortium for Citizens with Developmental Disabilities (CCDD) worked with Senator Chafee's staff over the summer of 1987 to translate the original group's legislative specifications into a finished bill, which was introduced to Senator Chafee on September 10, 1987 (S. 1673). Approximately one month later, Representative Florio introduced the House companion measure (H.R. 3454) (see Gettings, (1988) for a more complete discussion of the legislative history of S.1673/H.R.3454 up to the point of the bill's introduction, as well as for a comparison of S.1673 to Senator Chafee's earlier bills).

At the request of Senator Chafee (and with the strong support of organizations affiliated with the CCDD subcommittee), the Senate Finance Committee's Subcommittee on Health held a hearing on S. 1673 on March 22, 1988. At that hearing, testimony, both for and against the legislation, was taken from representatives of national organizations and other interested parties. Preceding and following this hearing, extensive efforts were made to gain broad co-sponsorship for the legislation in both the Senate and the House and to press for a hearing on Representative Florio's companion measure in the House. Ultimately, a House hearing was held on September 30, 1988. At this hearing, the House Subcommittee on Health and the Environment (of the House Committee on Energy and Commerce) also heard testimony on a bill (H.R.5233) introduced by Representative Henry Waxman (D-California) in August, 1988.

While the list of House and Senate co-sponsors of the "Medicaid Home and Community Quality Services Act of 1987" continued to increase through the end of the 100th Congress, neither the House nor the Senate decided to move the legislation along to the next step in the Congressional process ~ namely, a committee "markup" session on the bill. As a consequence, S.1673/HR3454 died with the end of the 100th Congress.

Senator Chafee has indicated that he plans to reintroduce his legislation when the 101st Congress convenes in January 1989. A commitment has been secured from Senator Bentsen, Chairman of the Senate Finance Committee, that a "markup" session will be placed on the Committee's docket early in 1989. Following markup, the bill will be voted on by the Committee and, if approved, will be referred to the Senate leadership to be scheduled for floor debate. Exactly when these events are likely to transpire is unknown as of this writing; but should the latest version of the legislation be favorably reported by the Finance Committee, it would mark the furthest stage of the legislative process that any of Senator Chafee's proposals has reached since the introduction of his first bill in 1983.

B. Description of the Legislation

The overarching goal of the "Medicaid Home and Community Quality Services Act of 1987" was to assist individuals with severe disabilities to attain or maintain their maximum potential for independence and capacity to participate in community and family life by: (1) requiring each participating state to provide an array of "community and family support services" for such individuals through its Medicaid program; and (2) limiting federal Medicaid payments on behalf of persons with severe disabilities in larger Title XIX-certified long term care facilities (i.e., those with 16 or more beds). The legislation contained several important provisions designed to address key problems in federal Medicaid policies as they affect persons with severe disabilities. The objective of this summary is to outline many of the principal provisions of the legislation; in the following subsections, an effort is made to discuss some of the key ramifications of the legislation as well as estimates of the bill's fiscal impact. [N.B., for a more detailed discussion of the bill's provisions, please see Gettings (1988)]

The key provisions of S.1673/H.R.3454 that should be highlighted include:

1. Eligibility. The legislation is intended to serve "individuals with a severe disability," defined in the bill as a person with a disability that would qualify him or her for Supplemental Security Income (SSI) benefits. The onset of the disability would have to have occurred before the individual reached the maximum age threshold. The initial age threshold is 22, with the upper-age limit increasing by one year for each fiscal year the legislation is in effect, until it reaches age 50. Section 1902(p) of the bill would be added to the Social Security Act in order to grant states the option of offering Medicaid coverage to any individual who:
 - a. met the SSI test of disability,
 - b. required (or whose family requires) community and family support services; and
 - c. would have been eligible for SSI benefits if he/she were residing in a Medicaid-reimbursable institution.

States electing this option would have to set forth in their state plans and implementation strategies the criteria to be used in identifying eligible individuals (or reasonable classifications of such individuals) and the extent of services authorized. Under existing statutes, a somewhat similar option is available to the states with respect to children with severe disabilities, except that the individual must require the level of care provided in a Medicaid-certified institution (i.e., a hospital, SNF, ICF or ICF/MR), rather than community and family support services, in order to qualify. The purpose of this amendment is to give states the choice of disregarding family income in determining the Medicaid eligibility of individuals with severe disabilities who are living with their families or relatives.

In addition, states electing to establish higher income eligibility standards for the receipt of institutional services would be required to apply the same standard to individuals with severe disabilities receiving non-institutionalized services. Under current law, a state may, at its option, establish a higher income standard for institutional eligibility so long as it does not exceed 300 percent of the federal SSI payment rate (Section 1903(f)(4)(C)). The proposed amendment would obligate a

state to use the same income standard for all individuals with severe disabilities (whether or not they were receiving institutional services), if they elected to set an income standard in excess of 100 percent of the federal SSI payment rate.

Finally, the effective date of a provision included in the 1986 "Employment Opportunities for Disabled Americans Act" would be revised, thus expanding the number of persons potentially eligible to receive CFS services. Under current law, any individual found to be eligible for Social Security adult-childhood disability benefits on or after July 1, 1987 is entitled to continued Medicaid coverage when they lose SSI eligibility solely due to the receipt of Title II (OASDI) benefits or an increase in Title II benefits. This amendment was designed to protect future Social Security "adult disabled childhood" beneficiaries from the precipitous loss of medical coverage (especially coverage of long term care services) due to the receipt of (or increases in) Social Security cash benefits.

A conforming amendment is included in the Act to make it clear that as long as an individual with a severe disability is eligible, or deemed (for purposes of Medicaid) to be eligible, for SSI benefits, he or she would be entitled to receive Medicaid benefits. The effect to this amendment would be to require those states that use a stricter test of disability than the federal SSI test (i.e., the so-called 209(b) states) to provide Medicaid coverage to individuals with severe disabilities on the same basis as states which use the SSI disability criteria in determining Medicaid eligibility.

Covered Services. Not later than the second fiscal year beginning after the enactment of the legislation, each state participating in the Medicaid program would have to amend its state plan to cover "an array of community and family support services which the State determines are appropriate...." A state would be required to cover at least the following services; case management services; individual and family support services; specialized vocational services; **and** protective intervention services. [N.B., Elsewhere in the bill, states are required to have a protection and advocacy system, the services of which are eligible for Medicaid-reimbursement.]

The following types of community and family support services (many of which are defined in greater detail in other sections of the legislation) could be covered under a state Medicaid plan on behalf of eligible individuals with severe disabilities if they are provided in accordance with the individual's written habilitation plan to a person living in a family home, foster family home or a community living facility:

- case management services;
- individual and family support services;
- specialized vocational services;
- protective intervention;
- habilitation services;
- case coordination services;
- educationally-related services;
- periodic interdisciplinary diagnostic and assessment services;
- personal assistance and attendant care;
- domestic assistance necessitated by the individual's disability;
- services to enable the individual to improve or maintain functional capabilities (including physical therapy, occupational therapy, speech and language pathology and audiology, respiratory therapy and non-aversive behavior intervention therapy);
- prostheses, orthoses, supplies, appliances, adaptive equipment, communicative aids and other functional assistive technologies and devices (including sensory aids) and rehabilitative technology services to evaluate, design, assemble, repair and maintain such

- equipment/aids/devices/systems (including training individuals and families in their use);
- preventive and therapeutic dental services;
- design and necessary/reasonable adaptation or modification of equipment, vehicles and housing;
- comprehensive outpatient rehabilitation facility services;
- purchase and maintenance of guide dogs and similar trained animals;
- services (other than board, lodging and basic foster care) provided by members of a family or household in which an eligible individual is living;
- support services to families and caregivers, including specialized training as well as in and out-of-home respite care; special transportation services;
- homemaker and home health services; chore services; crisis intervention; personal guidance, supervision, counseling, representation, and advocacy; appropriate preventive services to decrease the needs of eligible individuals for future services; and, any other services identified by the state and approved by the Secretary.

The following types of services may not be covered under a state's Medicaid plan as community and family support (CFS) services;

- room and board (other than room and board provided for less than six consecutive weeks and less than twelve weeks in a year as an integral but subordinate part of another CFS service listed above). Auxiliary payments to cover extraordinary food and housing costs attributable to a person's disability, however, may be treated as Medicaid-reimbursable. any service reimbursable under the AFDC program;
- cash payments;
- aversive behavior intervention, management or therapies;
- any Medicare-reimbursable service; any educational service which the state makes generally available to its residents without cost and without regard to income, except for educationally-related services; and, any service to an individual in a hospital, skilled nursing or intermediate care facility (including an ICF/MR or mental hospital).

Any costs incurred by a state in administering the provision of community and family support services would be treated as reimbursable administrative costs under the state's Medicaid plan.

3. State Assurances. The Act frames the organization of services within the context of a state's making key assurances to the Secretary of HHS and working out what is termed an "implementation strategy." In order to cover community and family support services under its Medicaid plan, a state would be required to furnish the Secretary with the following assurances:
 - a. The state will submit a state implementation strategy that meets the specifications outlined in Item 4 below. [N.B., The state implementation strategy is not subject to Secretarial approval but, nonetheless, must be submitted to HHS/HCFA.];

- b. The state will ensure that community living facilities "...are not unduly concentrated in any residential area";
- c. The state will report to the Secretary on the status of efforts to carry out its implementation strategy and comply with the Secretary's requests to correct or verify such reports;
- d. The state will cooperate with the Secretary in carrying out his responsibility to assess the state's compliance with its implementation strategy, including making available such records as the Secretary may reasonably request;
- e. The state will: (a) promulgate standards governing each element of community and family support services covered under its Medicaid plan; (b) monitor annually all providers of such services to assure that they are complying with applicable standards; and (c) take necessary steps to assure that such standards are promptly and effectively enforced;
- f. The state will comply with the maintenance of effort requirement contained in the legislation (see below);
- g. The state will safeguard the rights of all individuals with severe disabilities who participate in Medicaid-financed services;
- h. The state will ensure that all individuals with severe disabilities are granted equal access to available community and family support services, regardless of their place of residence or the nature/degree of their disability,
- i. The state will assure that eligible individuals who are placed in out-of-home care facilities are located in facilities as close to the home of their natural, adoptive or foster families as is consistent with their best interests; and
- j. The state will ensure that priority is given to providing vocational services in integrated work environments;

' A state's willingness to make these assurances (and accept scrutiny that they are being carried out) represents a condition of the Secretary of HHS approving a Medicaid state plan amendment to permit a state to gain FFP for the coverage of CFS services.

4. **State Implementation Strategy.** Leading up to a state's actually offering the services authorized under the Act, it must develop an "implementation strategy" that would include the following elements:

- a. **Institutional and Community Services Plans:** The state would be obligated to:
 - i. describe the extent and scope of community and family support services provided under: (a) the state Medicaid plan; (b) other federal or federally-assisted programs; and (c) non-federal programs;
 - ii. describe the extent and scope of services provided to eligible individuals who were residing in acute care hospitals, skilled nursing and intermediate care facilities (including ICF/MRs) and other large public and private facilities (i.e., with 16 or more beds) where a significant number of SSI recipients resided;
 - iii. set forth specific objectives and a projected schedule for expanding and improving community and family support services for

individuals with severe disabilities over the succeeding five year period (including planned sources of funding);

- iv. identify, within 18 months of date community and family support services were first covered under the state's Medicaid plan, the services each person residing in a large facility would need if transferred to a family home, foster family home, or community living facility. The individual and, as appropriate, his spouse, parent, guardian, appropriate family member or advocate would have to be afforded an opportunity to participate in this process;
 - v. arrange to transfer any eligible individual residing in a Medicaid-certified nursing home who was determined to need an alternative residential setting to such a setting within 40 months after completion of the needs assessment;
 - vi set forth specific objectives and a projected schedule (covering the succeeding five year period) for transferring other eligible individuals who are residing in large facilities (i.e., other than those residing in nursing homes) to more appropriate residential settings; where they will be eligible to receive CFS services; and,
 - vii. institute a pre-admission screening program to prevent the inappropriate placement of individuals with severe disabilities in nursing homes (i.e., SNFs and ICFs) not later than 18 months after the date on which community and family support services were first covered under the state's Medicaid plan.
- b. Placement Policies and Procedures: The state would be required to:
- i. observe the following policies and procedures in placing eligible individuals out of large facilities (i.e., those with 16 beds or more);
 - such individuals may be placed only in a facility or program that is capable of providing an appropriate array of services consistent with the individual's written habilitation plan;
 - priority must be given to placing such individuals in a family home, foster family home or community living facility (including a small, community-based ICF/MR);
 - individuals may be placed in large ICF/MRs only if the services they require are unavailable in the community in which they otherwise would reside; and,
 - while an individual is awaiting transfer from a nursing home he or she must be furnished active treatment services consistent with his/her written habilitation plan;
 - ii. observe the following procedures in transferring individuals from SNFs, ICFs, ICF/MRs and large board and care facilities to a family home, foster family home or community living facility,
 - develop a "community services transfer plan"
 - provide written notice to the individual and his/her spouse, parent, guardian, appropriate family member or advocate at least 60 days prior to the proposed transfer;
 - establish a procedure for granting affected individuals (or, as appropriate, their spouses, parents, guardians, appropriate family members, or advocates) an opportunity to appeal the transfer plan and have a hearing before an impartial hearing officer; and,

afford the individual the right to remain in the facility pending the outcome of any appeal (unless protective intervention is deemed to be necessary).

- c. **Quality Assurance:** The state would be required to set forth in its implementation strategy "...the component parts of a comprehensive, integrated quality assurance system that affords individuals with severe disability expanded opportunities for independence, productivity and integration...." As part of this system, a state would have to:
- i. promulgate standards governing each element of community and family support services covered under its state Medicaid plan, as well as each class of residential facility or living arrangement in which a significant number of eligible individuals reside. These standards would have to assure that services were:
 - based on timely assessments of the individual's needs and systematically organized to assure optimal individual development, independent functioning, productivity and community integration;
 - furnished in accordance with the individual's written habilitation plan and reflecting the individual's strengths as well as the services required to assist him/her to achieve more independent functioning with respect to health and physical development, receptive and expressive communications, cognitive functioning, mobility, self-direction, socialization, leisure time and vocational activities;

provided in a manner that maximizes opportunities for relationships between the individual and members of the surrounding community,

provided in community settings (homes, schools, job sites, etc.) where existing and newly acquired skills can be put to practical use;

designed to ensure that services provided to persons residing in community living facilities are furnished in settings other than the facility in which the individual lives (except where medically contra-indicated); and

designed to assist the individual in acquiring the functional life skills necessary to live independently and be integrated into the surrounding community;
 - ii. set forth the methods to be used in instituting and maintaining the state's quality assurance system;
 - in. outline methods and procedures to: (1) provide an opportunity for public input in the development of facility/service standards; (2) allow the state developmental disabilities planning council and protection and advocacy system to review proposed standards; and (3) respond to comments by the public, the DD council, and the P and A system regarding such standards;
 - iv. license or certify all facilities and programs that provide community and family support services covered under the state's Medicaid plan. All physical structures in which eligible individuals

either reside or receive program services would have to meet applicable state/local fire, safety, health and sanitation codes, and they would have to have interior and exterior features comparable to other residential structures in the surrounding neighborhood. A state, at its discretion, could require that specified classes of facilities/programs be accredited by a national accrediting body designed by the Secretary.

- v. establish a "system for conducting annual independent, third party evaluations of a cross-section of community and family support services provided under its state Medicaid plan. This system would have to include:
 - an analysis and validation of client-based data; periodic visits to a statistically valid sample of agencies or individuals providing such services; an assessment (of a statistically valid sample of eligible individuals receiving services, using reliable and valid instruments) to determine the extent to which services contribute to a person's making choices, the acquisition of positive social behaviors, improved social integration and participation in community life, increased productivity, consumer satisfaction, the physical comfort of the individual, the attractiveness/appropriateness of his/her living environment and the achievement of the goals/objectives outlined in the individual's written habitation plan; and a summary of findings and recommendations with regard to needed changes in state laws and administrative policies and practices.
- vi. conduct an annual assessment of consumer satisfaction with community and family support services;
- vii. organize a program of periodic assessments of the physical and social environment of residential settings by a review body composed of parents, guardians, relatives and neighbors of individuals with severe disabilities;
- viii. establish "a systematic methodology for assuring prompt correction of any deficiency identified...". This methodology would have to include;
 - a procedure whereby the provider could appeal any deficiency citation; a requirement for the submittal of a correction plan by the provider when deficiencies are identified. This plan must include a schedule for promptly eliminating such deficiencies;
 - a training and technical assistance program to assist providers in eliminating deficiencies; and a hierarchy of penalties for failure to comply with state standards, including termination of the provider's participation in the program.

Admissions to Institutions and Other Large Congregate Facilities. A state would have to spell out the steps it would take to: (a) restrict admissions to residential facilities that do not meet the definition of a family home, foster family home or community living facility (Le., larger

congregate care facility) through the use of community-based services; and
(b) identify the service needs of persons residing in such facilities

- e. Continuity of Services. A state would be required to:
 - i. make alternative provisions for any eligible individual who had been living in a Medicaid-financed facility or institution which ceased to provide care and services to the individual (except at the request of the individual or his/her representative); and
 - ii. establish procedures for ensuring the continuity of funding and the provision of services to an eligible individual when the entity through which he or she was receiving Medicaid-reimbursable services voluntarily discontinued operations or was terminated from the program.
- f. Public Participation. The state would have to "...afford the public an adequate opportunity to comment on the State's implementation strategy..." before submitting it (or annual revision thereof) to the Secretary.
- g. Staff and Agency Qualifications. The state would be required to establish methods and procedures for ensuring that:
 - i. each staff member of an agency providing community and family support services was: (1) fully qualified to perform any assigned duties; and (2) had received or would receive adequate training and retraining in the provision of services;
 - ii. each provider agency or organization maintained written personnel
 - policies;
 - iii. each provider agency or organization had access to needed technical assistance services.
- h. Protective Intervention. The state would have to set forth methods for assuring that protective intervention services were made available, where necessary, to individuals with severe disabilities. It also would be required to assure that the entity responsible for providing protective intervention services:
 - i. had daily, 24 hour access to every organization or agency responsible for providing Medicaid-reimbursable services to eligible individuals;
 - ii. was independent of any organization or agency responsible for providing services to such individuals; and
 - iii. had the legal capacity to intervene on behalf of such individuals when necessary to protect their rights.
- L. Parent Training. The state would have to specify the methods to be used in furnishing training and technical assistance to natural, adoptive and foster parents of eligible individuals.
- j. Case Management Services. The state would have to specify the steps that would be taken to ensure that each eligible individual receiving Medicaid-reimbursable community and family support services had access to case management services which were provided:

- i. by an entity that was organizationally independent of (and free of any conflict of interest with respect to) any entity furnishing ongoing direct services to individuals with severe disabilities;
 - ii. with sufficient frequency and intensity to ensure that the objectives outlined in the individual's written habilitation plan were achieved within the timeframes specified; and
 - iii. by a trained individual with a caseload that permitted him/her to visit each individual at least once a month.
- k. Management Information System. The state would be obligated to have in effect a management information system "...capable of collecting, storing and retrieving data on individuals who received (or were eligible to receive) community and family support services..."
- L. Appeals. The state would be required to spell out procedures for:
 - i. granting an individual or, as appropriate, his/her spouse, parent, guardian, appropriate family member, or advocate an opportunity for a speedy, impartial appeals hearing when the individual (or his representative) believed that he/she was being inappropriately served, denied appropriate services or scheduled for transfer from one living arrangement to another;
 - ii. providing affected parties with a written notice at least 60 days prior to any proposed transfer (except under emergency circumstances); and,
 - iii. advising affected individuals, their families and advocates of available alternative arrangements and services, the individual's right to choose among the available licensed/certified providers of services and their right to a fair hearing.
- m. Administration. The state must describe the methods to be used in administering community and family support services under its state Medicaid plan, including:
 - i. the specific roles and responsibilities of: (a) specified state and local governmental agencies in establishing policies governing the provision of such services and in providing such services (either directly or through arrangements with other public and private entities); (b) the agency responsible for providing protection and advocacy services; and (c) the community agencies and organizations responsible for providing community and family support services; and,
 - ii the steps to be take in recruiting and selecting community provider organizations/agencies.
organizations/agencies.
- n. Use of Medications and Behavioral Management Techniques. The state would be obligated to specify the criteria to be used in prescribing psychotropic and anti-convukant medications as well as behavior management techniques. In addition, the methods the state would use to ensure compliance with such criteria would have to be outlined in the state's implementation strategy.
- o. Supported Employment. The state would have to set forth the methods it would use to expand the number and types of integrated work settings and

. , the range of available supportive services that it would make available to eligible individuals 18 years of age or older.

- p. **Coordination with Education and Rehabilitation Agencies.** The state would have to outline methods for assuring that the provision of Medicaid-reimbursable specialized vocational and educationally-related services would be coordinated with state and local vocational rehabilitation and educational agencies.
- q. **Employee Protections.** The state would have to outline fair and equitable provisions (as determined by the Secretary in consultation with the Secretary of Labor) to protect the interests of public employees who were effected by the transfer of eligible individuals from public institutions to community or family living facilities. Maximum efforts would have to be made to provide for the employment of such persons, including arrangements designed to preserve employee rights/benefits and, where necessary, to train and retrain such employees. The state also would have to outline methods and procedures for assuring fair employment standards and equitable compensation for workers in private programs and facilities offering Title XIX-reimbursable services to eligible individuals.

In structuring its "implementation strategy" to address these areas, the legislation sets forth an extensive list of areas a state must address before it may receive Medicaid reimbursement for services covered under the legislation.

- 5. **Provisions Affecting Federal Payments to States.** In addition to authorizing federal financial participation in furnishing CFS services specified as reimbursable, the legislation has the following additional provisions which bear on federal Medicaid payments to states:
 - a. **State Maintenance of Effort.** A state must maintain the level of state and/or local support for services that it attempts to qualify for Medicaid reimbursement under the act and, further, commit to adjusting that level of Support to reflect the effects of inflation. In other words, a state must maintain its present level of fiscal effort or face a reduction in federal payments.
 - b. **Limits on Federal Payments to Larger Facilities.** Effective with the beginning of the first fiscal year beginning after the date of enactment of the legislation, federal financial participation (FFP) in the cost of SNF, ICF and ICF/MR facilities (with 16 or more beds) would be limited to the amount the state received on behalf of individuals with severe disabilities under 65 years of age in the previous fiscal year. This limitation, or freeze, on FFP would remain in effect indefinitely, except for amounts:
 - i. in excess of a six percent rate of inflation, as measured by the CPI; and
 - ii. necessary to implement a plan of correction resulting from a federal ICF/MR look behind review that involves a net reduction (or phase-down) in the facility's population (see item V below).
- This limitation would not apply to a SNF, ICF and ICF/MR facility which met federal standards (including standards governing appropriateness of admissions) and also either
- i. met the size and locational requirements of a community living facility,

- ii. had 15 or fewer beds (not including those occupied by staff members), was in operation on September 30, 1987, and had not increased its bed capacity, or
 - iii. was otherwise treated as a community living facility under the statutory definition of this term.
- 6. Waivers of Statewide and Comparability. A state would not be considered to have violated the statewide and comparability requirements of Medicaid law if it elects to phase in any new community and family support service (including the mandatory services specified above) over a three year period. By the end of such a period, however, the state would have to make the specified service available statewide and on a comparable basis.
- 7. Waiver of Freedom of Choice. A state would be permitted to disregard the "freedom of choice" requirement of the Act in furnishing case management services, if it found that waiving such requirements was necessary to the effective and efficient provision of services.
- 8. State Administration. The Governor of a state could assign responsibilities for performing specific management functions regarding the provision of community and family support services to agencies other than the single state Medicaid agency.
- 9. Protection of Rights. In order to qualify for Medicaid payments for community and family support services, a state would be required to have in operation a system to protect and advocate for the rights of individuals with severe disabilities who were eligible for Medicaid benefits. This system would have to be implemented by an agency which:
 - a. was independent of any provider of direct Medicaid-reimbursable services to eligible individuals;
 - b. had the authority to pursue legal, administrative and other appropriate remedies on behalf of such persons; and
 - c. had the authority to access client records in order to carry out its duties.

A state would be obligated to designate the existing protection and advocacy system established pursuant to the Developmental Disabilities Assistance and Bill of Rights Act to carry out such function. In addition, it would have to provide the Secretary with assurances that any Medicaid payments for protection and advocacy services would be used only on behalf of persons with severe disabilities who were eligible to receive Medicaid-reimbursable services.

- 10. Private Enforcement. "[A]ny person injured or adversely affected or aggrieved..." by an action of the state administering agency that violates the terms of the legislation would be permitted to file suit in federal district court for injunctive relief. The plaintiff in such a suit would be authorized to recover reasonable attorney's fees/costs from the defendant should he or she prevail in the case.
- 11. Payment Rates. The state would have to specify in its Medicaid plan the methods and standards it intended to use in establishing payment rates for community and family support services. Such methods/standards would have to result in payment rates that were "...reasonable and adequate to assure the provision of care and services..." that: (a) complied with applicable state and federal laws and regulations; (b) met quality and safety standards; and (c) assured eligible individuals reasonable access to community and family support services of adequate quality (taking into account geographic location and reasonable travel time for family and friends).

12. Establishment of a Bureau of Developmental Disabilities Services. The Secretary of HHS would be required to establish within HCFA a Bureau of Developmental Disabilities Services, which would be "...the principal office within the Department... for administering... programs under Title XIX... related to individuals with severe disabilities". The Bureau would have to be headed by a director, appointed by the Secretary in consultation with the HCFA Administrator.
13. Development Testing, and Dissemination of Outcome Measures and Personnel Standards. The Secretary would be responsible for developing, field testing and disseminating:
- a. reliable and valid instruments to assess the outcomes of Medicaid-financed services to eligible individuals, including outcomes in such areas as community integration, individual and family satisfaction, and the impact of environmental factors; and
 - b. competency-based personnel standards for agencies and organizations involved in providing Medicaid-reimbursable community and family support services to individuals with severe disabilities.

The Secretary would not be authorized to require states to use specific outcome indicators or personnel standards.

14. Assessment of State Compliance With the State Implementation Strategy. The Secretary, after consultation with the Secretary of Education and studying any recommendations made by HCFA's Bureau of Developmental Disabilities Services, would be required to conduct an annual assessment of each state's:
- a. compliance with the assurance it has provided the Secretary; and
 - b. progress in carrying out its implementation strategy, including the steps taken to:
 - expand the quantity and improve the quality of community and family support services;
 - develop essential support services necessary to maintain a responsive network of community and family support services (including the provision of training, technical assistance and crisis intervention services); and
- promulgate standards governing community and family support services, monitor compliance, and enforce such standards.

The Secretary also would be responsible for conducting "...annual assessments of the adequacy of the quality assurance components established..." under each state's implementation strategy. A state's implementation strategy would not be subject to Secretarial approval, provided it contained all of the components specified in the legislation.

15. Regulations. The Secretary would be responsible for issuing final regulations implementing the legislation prior to the beginning of the first fiscal year after the enactment date of the bill. These regulations would have to include provisions governing the preparation, public review, distribution and annual revisions in a state's implementation strategy. The bill provides, however, that the Secretary would not be authorized to:
- a. promulgate standards governing the provision of community and family support services; or

- b. withhold Medicaid payments for community and family support services prior to the issuance of final implementing regulations, provided the affected state complies with all of the requirements of the legislation.

While the bill contains other technical provisions, the provisions discussed above represent the main thrust of Senator Chafee's proposal for reforming present federal Medicaid policies as they affect persons with severe disabilities.

C. Commentary on the Legislation

In addition to the observations made concerning this legislation in the report itself, it is useful to highlight and discuss certain provisions of Senator Chafee's bill by directing the reader's attention to certain key facets of the legislation and their relationships to current issues associated with federal Medicaid policies as they affect services to persons with developmental disabilities.

To begin, it is important to note that the Chafee/Florio bill represents an attempt to achieve a wide range of objectives which a number of national organizations view as critical to the elimination of disincentives and perversities associated with existing federal Medicaid policies. In particular:

1. **Eligibility.** The aim in drafting the legislation was to assure that eligibility for CFS services would be completely decoupled from the "need for institutionalization" test. The legislation attempts to do this by substituting the SSI test of what constitutes a substantial physical or mental impairment as the standard for determining whether a person's disability indicates a need for CFS services. In addition, the legislation, through a variety of means, attempts to: (a) remove the "institutional bias" of Medicaid by requiring a state to use the same income and resource standards in testing an individual's eligibility for CFS services as it uses in determining financial eligibility for institutional services; and, (b) create additional options for covering persons who live at home or who might be denied eligibility because a state is classified as a "209(b)" state. In other words, compared at least to existing Medicaid long term care policy, the "portal" of eligibility under this legislation is very wide and may, at a state's discretion, be widened even further.

The following points should be made with respect to recipient eligibility under this legislation:

First, the legislation intends that persons who meet the SSI test of disability and a state's tests of financial need will be entitled to community and family support services. States, in other words, would be obligated to provide any or all of the mandatory services specified in the legislation to all eligible individuals who are found to need them. In addition, they would be permitted to choose among some 20 optional services that could be covered under the state's Medicaid plan on behalf of this same target population.

Basic Medicaid policy mandates that a state extend eligibility to all public assistance groups, including SSI recipients. In conjunction with the adoption of the SSI program in 1972, however, Congress permitted states which employed eligibility tests that are stricter than SSI to retain such tests if they elected to do so. Such states are referred to as "209(b)" states. At present, there are fourteen states in this classification. The particular eligibility provisions that depart from SSI criteria used by these states are highly variable. In some states, such provisions constitute a major obstacle to gaining eligibility for certain groups of persons with developmental disabilities; in others, the effects of such differing criteria are relatively minor.

Second, the SSI criteria that would be used as the basis of eligibility under the legislation is broader than the criteria employed in most states to assess the eligibility of persons for community services or the "mental retardation and other related conditions" criterion presently employed in the Title XIX program to test eligibility for Medicaid-reimbursable developmental disabilities services. These criteria, for example, would permit certain types of individuals with mental illness to qualify for services under the legislation.

Third, the provisions of S.1673/H.R. 3454 that would increase the age of "onset" of a severe disability progressively until it reached age 50 would further broaden the categories of individuals who would be entitled to receive services under the legislation by incorporating groups not presently served within state developmental disabilities service systems. (i.e., persons with severe disabilities originating in early adulthood in mid-life). [N.B., This provision was not a recommendation of the ad hoc task force which worked with Senator Chafee to develop the bill.]

In contrast to present Medicaid policies that permit a state considerable latitude in designating who is and is not eligible for Medicaid-reimbursable developmental disabilities long-term care services, the Chafee/Florio bill would establish a nationwide floor of eligibility, in order to insure that all persons with severe disabilities would have access to a minimum array of services. State latitude in determining the core population of eligible individuals who might receive CFS services would be more limited than under current law, although a state would have an improved set of options in granting eligibility to individuals who are not part of the core population.

Covered Services. The Chafee/Florio legislation was purposefully drafted to provide the state with a wide range of community and family service coverage options. Some 24 discrete services are enumerated as eligible for Medicaid reimbursement and a state is afforded the latitude of designating other services so long as they comport with the purposes of the legislation and are approved by the Secretary of HHS. In addition, extensive definitions are contained in the bill for many of the enumerated services; one reason for including such lengthy definitions was to prevent HCFA officials from establishing more restrictive definitions by issuing proscriptive regulations or administrative policies.

As noted earlier, the legislation would mandate that each state cover a core set of services (case management, specialized vocational, individual and family supports, and protective intervention) that the states would have to make available to all eligible individuals. Again, the aim of this requirement was to assure that all persons with severe disabilities had access to a basic set of services, regardless of the state in which they reside. The framers of the legislation were particularly interested in assuring that high quality case management services would be available to all persons (and, hence, the inclusion of extensive provisions describing the scope and range of such services that would be furnished to eligible persons) and to require states to cover individual and family support services before qualifying the costs of out-of-home services for Medicaid reimbursement.

At the same time, however, it is important to note that the legislation left intact the bulk of current statutes governing the ICF/MR program. No attempt was made, for example, to change the character of existing statutory provisions or mandate that regulations governing this program be revised to comport with the general aims of this legislation. Legislative provisions regarding the ICF/MR program were restricted to limiting the federal government's level of financial participation in the costs of larger, ICF/MR facilities. Apart from the provisions dealing with the cap

on payments to facilities with 16 or more residents, the Chafee/Florio bill was premised on the belief that states should be permitted to claim federal Medicaid payments for a wide range of community and family support services that would complement, but did not necessarily displace, the role of "small" ICF/MR facilities in federal statute.

3. Larger Facilities. Earlier versions of the Chafee/Florio legislation contained provisions that would have mandated the depopulation of larger, ICF/MR-certified facilities or, alternatively, would have progressively withdrawn federal Medicaid support from such facilities over a period of ten to fifteen years. S.1673/HJ13454, however, includes provisions to simply freeze the existing aggregate level of federal Medicaid payments on behalf of residents of ICF/MRs with sixteen or more beds (except during periods of high inflation or when federal "look-behind" survey results reveal significant deficiencies that require the expenditure of additional funds to bring a facility into compliance with federal ICF/MR regulations).

The restriction on Medicaid payments to states for the costs of services furnished in larger facilities served several different objectives in the overall context of the bill. First, the restriction was viewed as a necessary step to assure that the fiscal impact of the legislation would be limited. By limiting payments to large ICF/MR facilities, the drafters of the legislation recognized that it would be possible to support a broader range of community and family support services on behalf of a larger target population without triggering an overall increase in the rate of federal Medicaid outlays. Second, key supporters of the legislation viewed such a restriction as an essential step toward eliminating the states' reliance on large congregate facilities. Third, some supporters of the legislation viewed the payment restriction as a means of preventing the continued depletion of resources to maintain large, outmoded public residential centers, which ultimately would work to the detriment of efforts to expand community-based services.

Without a doubt, the so-called "freeze" on payments to larger facilities has emerged as the single provision of S. 1673/H.R. 3454 around which opposition to the legislation has coalesced. Some institutional parent groups, for example, view this provision as a major threat to the long-term security of services furnished to their sons and daughters who reside in larger facilities. Public employee unions, while recognizing that the role of larger, state-run facilities is receding, nonetheless strongly oppose a restriction on federal payments which could prompt an acceleration in the closure of such facilities. Some private provider agencies also have expressed concern that, since the freeze covers not only state-run centers but larger privately-operated facilities, states might attempt to preserve their own institutions by directing the main impact of the freeze toward private facilities.

In addition, the concept of a freeze evokes considerable opposition in the House of Representatives (and, particularly, on the part of Representative Waxman). It must be kept in mind that, over the past several years, the House has successfully rebuffed numerous attempts by the Reagan Administration to impose a general, across-the-board cap on federal Medicaid payments to the states. Finally, while initially voicing a willingness to accept restrictions on federal payments to larger ICF/MR facilities in exchange for broader-based coverage of community and family support services, state MR/DD agencies have recently expressed renewed reservations about the proposed cap in view of the rising costs of ICF/MR services that has resulted from increased federal regulatory oversight of ICF/MRs. They point out that the higher "threshold" of regulatory compliance now being imposed by HHS/HCFA makes a cap infeasible from a state budgetary perspective.

No doubt, the issue of maintenance of open-ended federal financial participation in the cost of operating larger ICF/MR facilities will continue to be a bone of contention in the renewed debate concerning the Chafee legislation in 1989.

Federal and State Roles. A great deal of attention is paid in S. 1673 and H.R. 3454 to the appropriate roles of the states and the federal government in managing Medicaid-reimbursable community services and how accountability for such expenditures can be best assured. The legislation rejects the notion that the Secretary of HHS should be given unilateral responsibility to regulate the provision of the Medicaid-reimbursable services that would be authorized under the bill. Indeed, the level of Secretarial involvement in program administration would be purposely restricted, largely as an outgrowth of the states' recent experiences in dealing with an Administration bent on using administrative policies to constrain federal outlays.

Recognizing that Congress was unlikely to approve legislation that granted the states *carte blanche* authority in utilizing federal funds to support community and family support services to persons with severe disabilities, the framers of the legislation focused on three strategies to assure Congress that federal dollars would be used to support intended services while avoiding the perceived pitfalls of intrusive federal regulation and oversight of the delivery of such services. In particular:

First, extensive and extraordinarily detailed statutory provisions were drafted to obviate the need for Congress to assign the Secretary the responsibility of issuing regulations administratively defining the steps a state would need to take to implement the legislation. Extensive statutory provisions were viewed as necessary to: (a) assure Congress and the interested public that the basic intent of the legislation would be followed in each state; and, (b) restrict the ability of a hostile federal Administration to limit the scope and range of services that states were allowed to provide in order to achieve federal budgetary objectives.

Second, the reliance on state "assurances" as a precondition for approval of a Medicaid state plan amendment to cover CFS services was intended to avoid subjecting state plans to inappropriate levels of federal review while granting each state considerable flexibility in the way in which it elected to carry out various statutory requirements.

Third, the requirement that each state develop an implementation strategy represented a means of assuring that whatever measures a state took to back up its assurances would be subject to public scrutiny and participation across the full gamut of issues that affect the provision of services to persons with severe disabilities.

In addition, the legislation would provide each state with the option of reassigning Medicaid program responsibilities to the state MR/DD agency, in order to permit a state to institute a unified approach to program administration. Lastly, to achieve the same ends at the federal level, the bill would require the Secretary to consolidate federal responsibilities for administering Medicaid-financed services for persons with developmental disabilities in a single bureau of the Health Care Financing Administration.

In many respects, these elements of S.1673/HJ13454 are the most complex and difficult to understand in the entire bill. The drafters of the Chafee bill were attempting to define a new basis of state-federal interaction in overseeing and regulating Medicaid-financed services. In part, the complexity of the legislation also stems from efforts to reflect in the bill's requirements emerging points of view regarding contemporary "best practices" in the provision of services and methods of assuring program quality. For example, the specifications regarding case management services are extremely detailed in comparison to those used by Congress when it authorized the provision of "targeted case management services" as an optional Medicaid state plan coverage in 1986 (through the adoption of

Section 1915(g) of the Social Security Act). These provisions not only describe, in detail, the scope and range of case management services but also reflect the view that case management services ought to be separated administratively and organizationally from the provision of direct client services.

In summary, then, the Chafee/Florio legislation represented an effort to address many different Medicaid policy problems while attempting to establish a new ideological orientation for employing Medicaid dollars on behalf of persons with developmental disabilities. For example, in requiring a state to cover a relatively large (by present day standards) target population and agree to furnish a minimum array of services to such individuals, the legislation represents a noteworthy departure from the conventional manner in which Congress has changed Medicaid policies: namely, by broadening the service options a state may elect to provide, rather than mandating that a state furnish particular types of services. The supporters of the legislation believe that such a departure from conventional practice is necessary to resolve interstate variations in the scope and range of services furnished to persons with severe disabilities.

The legislation's ideological bent is evident in many differing ways, including the institutional "freeze," its strong articulation of client rights (including the right to individually sue a state for the alleged failure to effectively carry out the provisions of the legislation), prohibitions against the use of "aversive" behavior modification techniques, and the call for "independent" case management services. As a consequence, the legislation attempts to move beyond mandating greater emphasis on community-based services to attempting to change the framework within which such services are furnished.

Finally, the legislation's attempt to resolve the thorny questions associated with federal and state responsibilities for implementing the legislation are noteworthy and — if the legislation were to be enacted — potentially precedent setting. At the same time, the effort to shield program management from intrusive federal oversight has raised significant concern on the part of some members of Congress as to whether the states can be entrusted to carry out the mandates of the legislation.

In conclusion, it is fair to say that the Chafee/Florio legislation is far more than an attempt to "tinker" with present Medicaid policies. Instead, the legislation tried to substantially redefine the overall basis for federal Medicaid assistance to the states on behalf of persons with severe disabilities.

D. Fiscal Ramifications

As was noted in Chapter IV of the report, estimates of the potential fiscal impacts of S.1673/H.R.3454 are highly divergent. Depending on the source of the estimate, the legislation would result in a net reduction of federal Medicaid outlays on behalf of persons with developmental disabilities or have ~ even by Washington standards ~ enormous fiscal impacts. It is useful, therefore, for the reader to have an understanding of the basis of this fiscal impact estimate, especially since the potential cost of the legislation undoubtedly will play a large role in determining its prospects for adoption.

The Congressional Budget Office (CBO) is responsible for estimating the fiscal impact of legislation introduced in Congress. In September and October of 1988, CBO furnished written estimates of the fiscal impact of S.1673/H.R. 3454 (as well as Representative Waxman's H.R.5233; see Appendix B of this report). In estimating the fiscal effects of the Chafee/Florio bill, CBO focused on two aspects of the legislation: (a) the effects of the freeze on payments to the states for services furnished in larger ICF/MRs; and, (b) the ramifications of the expanded coverage of community and family support programs. In addition, CBO estimated the additional administrative costs that would be associated with implementing and maintaining CFS services as well as the other administrative requirements contained in the legislation.

For the five-year period, commencing in federal FY 1989, CBO estimates that the Chafee/Florio bill would have the following impact:

Estimated Fiscal Impact of H.R.3454
Congressional Budget Office
Table 1

ESTIMATED FEDERAL COSTS
(millions of dollars)

	1989	1990	1991	1992	1993
Increase in Recipients and Costs: Community Services	0	0	335	750	1140
Limitation on Payments to Institutions	0	-310	-640	-990	-1365
Administrative Costs	30	35	70	80	110
TOTAL	30	-275	-215	-160	-115

Source: CBO, 1988

With regard to expenditures for community and family support services, CBO's estimates were based on the following assumptions:

First, CBO assumed that states would require an extended period of time to develop their implementation strategies, secure Secretarial approval for Medicaid state plan amendments, and begin to actually provide Title XIX-reimbursable community and family support services, as authorized under the legislation. Based on the assumption that the Chafee/Florino bill became law on January 1, 1989, for example, CBO estimated no effect on federal payments for community-based services until federal FY 1991 (the fiscal year commencing October 1, 1990 or 21 months following passage).

Second, CBO estimated that, by FY 1993, the number of persons receiving CFS services would total 115,000 persons, including 24,000 individuals whom the states would transfer from larger ICF/MR-certified facilities in response to the freeze on Medicaid payments to such facilities. CBO's estimates attribute the remaining increase in the number of recipients to the extension of CFS services to: (a) 30 percent of an estimated 350,000 children who receive SSI; and, (b) another 105,000 adults who would choose to enroll in the SSI program and, hence, become eligible for Medicaid in order to receive community services authorized under the legislation. In each case, CBO assumes that only 40 percent of potential enrollees would actually be offered and receive CFS services. Finally, CBO attributed a relatively small impact to the selection by the states of other optional eligibility coverages offered under the bill (only 5,000 additional persons would become eligible as a result of these provisions, according to CBO's estimates).

Furthermore, CBO assumed that the states would encounter difficulties in expanding the supply of services needed to meet new demands. This assumption influences CBO estimates regarding when states would actually begin to make claims for CFS services and the degree of participation in such services in future years. [N.B., CBO trimmed its estimate of FY 1993 costs by approximately 15 percent due to the assumption that the supply of services could not be expanded as rapidly as the demand for services increased.]

- In terms of the costs of services, CBO employed estimates based on the costs of services furnished by the states under their HCB waiver programs as well as other data. CBO assumed that costs would vary with the severity of disability and, hence, attributed a higher cost to serving persons transferred from larger facilities than non-institutionalized persons who would be enrolled in CFS services.

Finally, in CBO's judgment, the state "maintenance of effort" requirement would require the states to come up with additional federal matching dollars to access increased federal Medicaid payments for CFS services;

hence, the degree to which states would be able to utilize existing, unmatched dollars as a means of accessing increased federal payments would be limited, according to CBO's thinking.

CBO noted that its estimates of this aspect of the Chafee/Florio legislation are subject to a considerable number of uncertainties, including the degree to which "new users" would step forward to participate in the Medicaid program as a result of the legislation. In addition, it must be noted that CBO's estimates throughout this facet of its analysis are based on a variety of data sources, some of which may not constitute an entirely satisfactory basis for preparing fiscal impact estimates.

In terms of the effects of the cap on institutional expenditures, CBO's estimates are based on current trends in ICF/MR spending. In particular, CBO notes that its "baseline" estimate of projected spending increases in the ICF/MR program is an 11.5 percent annual rate of growth. The "baseline" constitutes CBO's estimate of spending in the absence of any change in current law. Noting that 82 percent of all ICF/MR beds are located in facilities serving 16 or more persons, CBO attributed an equivalent level of spending to such facilities and then estimated the federal budgetary savings that would be derived as a result of avoiding the 11.5 percent rate of increase in spending in such facilities due to the bill's proposed freeze on federal payments. In developing these estimates, CBO assumes that states would transfer 5 percent of the residents in large facilities to CFS services each year to mitigate the effects of the freeze and offset the remaining loss in federal financial participation through increased state appropriations.

Finally, with regard to administrative costs, CBO attributed a relatively high impact to the Chafee/Florio legislation, due mainly to the bill's requirements dealing with client assessment and quality assurance. At full implementation, CBO estimated that the average state would have to hire an additional 60 staff members "to meet the requirements of the act." In addition, CBO projected that HCFA would require an additional 50 staff positions to carry out federal responsibilities under the legislation.

As shown on the table above, CBO's overall estimate of the fiscal impacts of the Chafee/Florio legislation is that it would result in a net reduction in federal outlays in each year in which the freeze on institutional expenditures was applied. The five-year estimate is that federal outlays would be reduced by \$730 million. In other words, in CBO's view the freeze on institutional reimbursements will more than offset increased federal spending for CFS services as well as state/federal administrative costs. It also might be noted that, due to the freeze and CBO's view that the legislation's maintenance of effort requirement will necessitate new state appropriations to match federal payments for CFS services, state and local spending under the legislation is expected to rise substantially over the five-year period covered by CBO's estimates. By FY 1993, CBO estimates that state/local spending would be \$1.7 billion higher than under current law.

In CBO's opinion, then, the likely fiscal ramifications of the Chafee/Florio legislation are: (a) reduced total federal outlays on behalf of persons with developmental disabilities; (b) a reconfiguration of this reduced level of federal assistance from institutional to CFS services; and, (c) a major shift in program financing from the federal government to the states. Should the freeze on payments for larger Medicaid-certified facilities be deleted from this legislation, however, CBO's estimates of the effects on Medicaid spending for community and family support services would mean that a rather significant allowance of new spending

authority would have to be made in the Congressional budget resolution in order to account for the increased outlays that would be triggered by the bill.

In sharp contrast to CBO's estimates of the fiscal impact of the Chafee/Florio legislation, the Department of Health and Human Services has prepared its own preliminary estimates of the fiscal impacts of the Chafee/Florio bill. HHS has estimated that the legislation would trigger a net increase of \$700 million in federal Medicaid spending during the first year following enactment of the bill (compared to estimates of spending under current law), rising to \$1.3 billion in the second year, and thereafter rising progressively due to the effects of inflation. (ASPE/HHS, 1988) While the detailed assumptions that underlie these estimates are not available, it is clear that these estimates stem from two key disagreements with CBO's assumptions. In particular:

HHS believes that the states would submit Medicaid state plan amendments and begin claiming federal reimbursement for eligible CFS services far more quickly than CBO believes.

In large part, HHS bases its assessment that the states would move rapidly to take advantage of the Chafee/Florio legislation's broadened coverage of community and family support services on the fact that state's have a reservoir of approximately \$2 billion in state spending for community services that currently is not used to match Medicaid dollars. Since a substantial share of the services supported by this spending would qualify as CFS services under S.1673/H.R.3454, the states could readily gain additional federal payments without substantially increasing their own spending in this area.

At the heart of these striking differences in these two estimates of the potential fiscal impacts of the Chafee/Florio legislation is the true effect of the "maintenance of effort" provision of the legislation. CBO has interpreted this provision to mean that a state would have to supply additional state/local funds over and above present spending levels in order to access increased federal payments for community and family support services. HHS, on the other hand, believes that the effect of the "maintenance of effort" provision would be to prevent a state from reducing its present level of spending while permitting currently available state/local funds to be counted as matching dollars for services that are eligible for Medicaid reimbursement under the Chafee/Florio legislation. In other words, dollars currently appropriated and not otherwise already employed as Medicaid matching funds could be used to leverage additional federal payments.

In point of fact, determining the potential short or long-range fiscal impacts of the Chafee/Florio legislation is a complex undertaking. Ultimately, the fiscal impacts of the legislation would be determined by the reactions of states to the provisions of the final legislation. As in nearly any other federal-state program, it is likely that these reactions would vary considerably from state-to-state. The freeze on payments to large facilities, for example, might prompt some states to move quickly to submit Medicaid state plan amendments to access additional federal funding for community-based services, in large part to offset the effects of the freeze. In addition, it must be kept in mind that the most relevant effect of the "maintenance of effort" provision is to require states to increase total expenditures for community and family support services that could be qualified for Medicaid reimbursement under the legislation. In most states, there is little doubt the demand for services is such that utilization rates could increase rapidly, assuming that additional service capacity could be brought on line to accommodate such demand.

The ability of states to expand existing community service capacity can be expected to vary considerably. Undoubtedly, a key factor that would affect such capacity building is the degree to which states employ the additional federal funds that could be leveraged through existing state dollars to enhance payments to provider agencies. To the extent that states use additional federal dollars to do so, spending may increase rapidly in the short-term.

On the other hand, if states react conservatively to the legislation (e.g., by employing the bill's provisions to phase in implementation and/or remain within the boundaries of the mandatory service elements), spending for community and family support services could be expected to increase more slowly.

In addition, another key variable in calculating the bill's ultimate fiscal impact would be the extent to which the freeze on payments to larger facilities might prompt states to step up efforts to reduce populations in state or privately operated ICF/MR facilities in order to avoid having to substitute state dollars for the federal dollars that would no longer be available to support any actual increases in the cost of operating larger ICF/MRs. As noted in Chapter HI, the ability of states to accelerate the pace of "deinstitutionalization" may be limited. To the extent that federal oversight activities continue to result in an escalation in state spending on such facilities, therefore, many states might be hard-pressed to expand community-based services as rapidly as supporters of the Chafee/Florio legislation would like.

APPENDIX B:

THE WAXMAN LEGISLATION

APPENDIX B: THE WAXMAN LEGISLATION

A. Legislative History

Congressional debate surrounding Medicaid reform legislation took a new and potentially important turn in August 1988 when Representative Henry A. Waxman (D-CA) introduced a bill (H.R. 5233) which would make substantial modifications in current law as it affects the provision of Title XIX-reimbursable services to eligible persons with developmental disabilities. As Chairman of the House Subcommittee on Health and the Environment and a forceful advocate for programs to help the poor, Waxman is generally recognized as the most influential Member of the House when it comes to formulating Medicaid policy. Although he has fought hard (and with remarkable success) over the past eight years to protect the Medicaid program from the ravages of Reagan Administration-inspired budget cuts, Waxman has been unwilling to endorse the "Medicaid Home and Community Quality Services Act" (S.1673/HR3454).

Earlier in 1988, Waxman's aides announced they had been instructed to develop a bill that responded to his criticisms of the Chafee/Florio bill. H.R. 5233 represented the product of the staffs work. On September 30, 1988, the Subcommittee on Health and the Environment held a hearing at which testimony was taken on H.R. 5233; in addition, testimony also was received on H.R. 3454, the House version of the Chafee/Florio legislation. While much of the testimony presented at this hearing paralleled the views expressed at a March 1988 hearing on S. 1673 before the Senate Finance Committee's Subcommittee on Health, specific points were raised with regard to provisions of H.R. 5233 that many national organizations believed would be problematic or were not sufficiently responsive to the problems associated with current federal Medicaid policies affecting persons with developmental disabilities.

In his introductory remarks at the hearing on H.R. 3454 and H.R. 5233, Representative Waxman pointed out that the present imbalance in the use of Medicaid funds between institutional and community services had prompted a considerable debate about present federal policies; a debate that, in his view, was divisive. Representative Waxman characterized his legislation as an attempt to redirect the debate surrounding current Medicaid policies in a more constructive direction. The basic purposes of H.R. 5233 were characterized by Waxman in the following manner: (1) to increase the availability of high quality community services; and, (2) to improve the quality of institutional services paid for through the federal-state Medicaid program. He further characterized his legislation as the next logical step in an incremental reform of the Medicaid program as it relates to services to persons with developmental disabilities.

Representative Waxman's staff suggested that H.R. 5233 was an initial attempt to flesh out legislation and stimulate further discussion, rather than a finished product. The intent all along, they said, was to "put a bill on the table" to elicit comment, with the intent of utilizing such comments to redraft the legislation for possible introduction and legislative consideration during the 101st Congress. Following the adjournment of Congress in October 1988, Representative Waxman's staff have pressed various national organizations for specific comments on H.R. 5233, including detailed suggestions for modifying provisions of the bill which such groups viewed as problematic. Waxman's staff has stated that its goal is to have a revised bill ready for introduction early enough in the 101st Congress to permit any potential fiscal impacts that might be associated with the legislation to be reflected in the first Concurrent Budget Resolution for FY 1990 which will serve as a blueprint for the consideration of all federal legislation involving new spending during the upcoming year. Representative Waxman's staff points out that, unless such spending assumptions are built into the Congressional budget resolution by the early spring, there would be virtually no prospect that the House could act on such a measure during 1989.

There is no doubt that Representative Waxman, by virtue of his stature in the House, is a force to be reckoned with in any effort to secure basic reforms in present Medicaid policies as they affect persons with developmental disabilities. While his past interest in this area of policy has been relatively limited, he played a major role in enacting the HCB waiver authority and the "targeted case management" state plan option and is widely recognized for his efforts to improve Medicaid-financed long-term care services. The introduction of H.R.5233 was viewed by many as a signal that Representative Waxman planned to play a more proactive role in efforts to rework Medicaid policy in the area of developmental disabilities services. The policy changes envisioned by H.R.5233, therefore, provide important clues regarding the types of changes that Representative Waxman is willing to consider, as well as the basic parameters he expects Congress to follow in revising current Medicaid policies.

The next subsection describes the basic provisions of the legislation. The description is followed by a commentary on the bill. In addition, the Congressional Budget Office's estimates of the projected fiscal impacts of the legislation is discussed in the final subsection.

B. Basic Structure of the Waxman Bill

The "Medicaid Quality Services to the Mentally Retarded Amendments of 1988" is divided into five titles. Title I would authorize the states to offer community habilitation services as an optional coverage under their Medicaid plans. It also would modify the Medicaid HCB waiver authority and require the Secretary of HHS to develop and the states to utilize a uniform methodology for evaluating the quality of such community services. Title II of H.R. 5233 would establish statutory "conditions of participation" applicable to habilitation (ICF/MR) facilities, plus rewrite existing law as it applies to the survey and certification of such facilities as well as the enforcement of federal standards in such facilities. All applicants for admission to habilitation (ICF/MR) facilities would have to be screened prior to admission under the terms of Title III of the Waxman bill; furthermore, residents of such facilities would have to be reviewed annually to assure that they still were qualified to receive such services. Title IV of the bill would add new statutory provisions governing Medicaid payments to habilitation (ICF/MR) facilities or to establish Medicaid-funded community habilitation services. This title of the bill also would provide explicit authority for state mental retardation/developmental disabilities agencies to carry out Medicaid administrative functions and qualify for federal reimbursement to cover related costs. Title V of the bill would add provisions related to the protection of public employees.

1. Optional Community-Based Services

Section 101 of H.R. 5233 would permit the states to provide "community habilitation services" as an optional coverage under their state Medicaid plans. At the present time, the states may only cover such services under Medicaid HCB waivers, which are time-limited and subject to the approval of the Secretary of HHS. In approving HCB waivers, the Secretary, as a general practice, limits the number of participants in Medicaid-reimbursable home and community-based services to the current and projected capacity of ICF/MR facilities, statewide. Consequently, there are strict limits on the number of individuals that a state may qualify for such services.

Such optional community habilitation services, under the terms of the bill, could be provided "...without regard to whether or not individuals who receive such services have been discharged from a nursing facility or habilitation facility". Section 102 of the bill also would delete the existing "prior institutionalization" requirement applicable to the provision of prevocational, educational and supported employment services under a Medicaid home and community-based waiver program.

A state electing to cover optional community habilitation services under its state plan would be obligated to provide assurances that the interests of affected employees would be protected. The specific assurances a state would be required to provide are explained in the discussion of Title V of the bill below.

States would be permitted to offer community habilitation services under their Medicaid state plans both to categorically eligible recipients (i.e., those who qualify for SSI and AFDC benefits) as well as to individuals who fall into a newly created optional categorically eligible group. This latter group would consist of non-Medicaid-eligible persons who would be eligible for Title XIX services "...if they were in a medical institution" and who, in the absence of the required community habilitation services, "...would require the level of care provided in a habilitation [ICF/MR] facility the cost of which could be reimbursed under the state [Medicaid] plan".

In order to qualify for Medicaid reimbursement, community habilitation services provided in supervised residential settings would have to meet standards promulgated by the Secretary of HHS. These federal standards would have to be issued no later than October 1, 1989 and would have to include provisions governing client rights and protections, case management, the use of comprehensive functional assessments, the process of developing, monitoring and revising individual program plans, the use of a uniform client performance accounting system and the application of minimum health, safety and sanitation rules.

The term "community habilitation services" is defined in the bill as:

- (A) services designed-
 - (i) to assist individuals in acquiring, retaining, and improving self-help, socialization, and adaptive skills necessary to function successfully in a home or community-based setting, or
 - (ii) to assist individuals in participating in community or other activities;
- (B) includes (except as provided in subparagraph (C)) such prevocational, education, supported employment, and other supportive services as the State determines to be necessary and effective in promoting the individual's capability of engaging in major life activities with other individuals, including employment and participation in community activities; but
- (C) does not include--
 - (i) special education and related services (as defined in section 602(16) and (17) of the Education of the Handicapped Act (20 U.S.C. 1401(16), (17)) which otherwise are available to the individual through a local education agency, and
 - (ii) vocational rehabilitation services which otherwise are available to the individual through a program funded under section 110 of the Rehabilitation Act of 1973 (29 U.S.C. 730); and
- (D) does not include services furnished in a supervised residential setting unless the setting meets such standards for such setting (including standards relating to client rights and protections, case management, the use of comprehensive functional assessments, the process of developing, monitoring, and revising individual program plans, the use of a uniform client performance accounting system, and the application of minimum health, safety, and sanitation

rules) as the Secretary shall establish by regulation by not later than October 1, 1989; and

- (E) does not include room **and** board, consisting of non-personnel costs directly attributable to-
 - (i) the purchase of food on behalf of clients, (ii) the costs of property,
 - (iii) the purchase of household supplies not otherwise employed in the provision of covered services,
 - (iv) utility expenses, and
 - (v) costs of facility maintenance, upkeep, and improvement, other than such costs for modifications or adaptations to a facility required to assure the health and safety of residents or to meet the requirements of the applicable life safety code.

This definition is a modification of the statutory definition of "habilitation services" which currently applies to services provided under a Medicaid home and community-based waiver program (Section 1915(c)(5) of the Social Security Act). The major differences between the proposed and the existing statutory definitions are that the proposed definition would: (a) explicitly limit the provision of such services to those which "...assist individuals in participating in community or other activities"; (b) make Medicaid reimbursement for residential habilitation services subject to compliance with federal standards to be promulgated by the Secretary of HHS; and (c) add an explicit statutory definition of non-reimbursable room and board costs.

States would be permitted to cover community habilitation services under their state Medicaid plans, effective October 1, 1988, "...without regard to whether or not final regulations to carry out such amendments had been promulgated..." by the Secretary as of that date.

Section 101 of the bill also would define the term "mentally retarded", for purposes of the receipt of Medicaid-funded habilitation (ICF/MR) facility services and community habilitation services, to encompass "related conditions". The term "related conditions", in turn, would be defined in exactly the same way as it is in current federal Medicaid regulations (42 CFR 435.1009) — i.e., to include persons with severe, chronic disabilities attributable to cerebral palsy, epilepsy or "...any other condition, other than mental illness, found to be closely related to mental retardation..." Section 101 of the bill also would prohibit a state from restricting an individual's freedom to choose among approved providers of community habilitation services. This latter provision simply underscores the applicability of the so-called "freedom of choice" principle that applies to provision of all Medicaid-reimbursable services.

Quality Assurance for Community Habilitation Services

The Secretary of HHS, under Section 103 of H.R. 5233, would be required to develop, through demonstration projects and contracts, outcome-oriented instruments/methods of evaluating the **quality** of Medicaid-supported community habilitation services. The deadline for completing work on these instruments/methods would be January 1, 1991. In order to qualify for continued Medicaid support of community habilitation services, a state would be required to use the instruments and methods developed by the Secretary in evaluating such services and to discontinue payments to any provider found to be furnishing sub-

standard services. This requirement would apply to community habilitation services reimbursed under a HCB waiver as well as under the new optional state plan coverage.

3. Requirements for Habilitation Facilities

Section 201 of the draft bill would incorporate in federal statute detailed operating standards applicable to "habilitation facilities" (currently referred to as ICF/MRs). The general format and some of the specific contents of these standards closely parallel the provisions of Section 1919(a) through (d) of the Act (applicable to nursing facilities), as added by the Omnibus Budget Reconciliation Act of 1987 (OBRA-87; P.L. 100-203). These nursing facility "conditions of participation" have been modified to include key provisions of the revised ICF/MR regulatory standards, published by HHS's Health Care Financing Administration (HCFA) on June 3, 1988. Among the specific areas covered in these statutory operating standards are:

- the scope of services and activities allowable under an individual's program plan;
- the development and contents of an individual program plan;
- the completion of a comprehensive functional assessment of a recipient's service needs; preadmission screening of persons with mental retardation and related conditions;
- the provision of services and activities;
- physician supervision of services and clinical records;
- requirements related to clients' rights;
- admission policies;
- protection of clients' funds;
- licensing and life safety codes; and
- sanitary and infection control and physical environment.

A habilitation facility would be required, under the terms of the draft bill, to provide each client, in accordance with his or her individual program plan, with "continuous active treatment services" that are directed toward: (a) "the acquisition of behaviors necessary for the client to function with as much self-determination and independence as possible, behavioral and social skills necessary for the client's maximum possible individual independence;" and (b) "the prevention or deceleration of regression or loss of current optimal functional status". Such services must be coordinated by a qualified mental retardation professional.

The definitions of the terms "habilitation facility" and "active treatment" contained in the bill are lifted, practically verbatim, from the revised federal ICF/MR standards. In addition, by no later than October 1, 1989, the Secretary would be instructed to develop and promulgate "an operational definition of continuous active treatment that promotes a consistent assessment of whether a habilitation [ICF/MR] facility is in compliance with..." the new statutory "conditions of participation".

Finally, the Secretary of HHS would be responsible for: (a) establishing guidelines for a state's appeal procedures involving transfers and discharges from a habilitation facility; and (b) criteria for assessing habilitation facilities' compliance with a number of administrative and clinical requirements. These responsibilities would parallel the responsibilities assigned to the Secretary with respect to nursing facilities under Section 1919 of the Act.

4. Survey and Certification Process

Section 202 of the bill would add new statutory requirements governing the conduct of surveys and certification of habilitation facilities. In addition, it would transfer responsibility for surveying and certifying state-operated habilitation (ICF/MR)

facilities from the state survey agency to the Secretary. These requirements are identical, in most respects, to the provisions of Section 1919(g) of the Act (applicable to nursing facilities), as added by OBRA-87. Among the key requirements would be:

The state would have to maintain a program of periodic educational opportunities for residents and their parents/guardians regarding applicable certification regulations and policies.

The Secretary would be responsible for developing, testing and validating a survey protocol, which states would be required to follow in reviewing habitation facilities once it was promulgated.

Each habitation facility would be subject to an annual, unannounced survey. HCFA could review a state's procedure for scheduling/conducting such surveys.

- The Secretary also would be responsible for establishing the minimum qualifications of survey team members.
- The state would be required to implement programs to reduce survey inconsistencies.

Each survey would have to be conducted by a multidisciplinary team of professionals who were not subject to a conflict of interest.

The Secretary would be required to conduct a comprehensive training program for federal and state surveyors. No individual could serve on a survey team unless he or she completed the required training course and passed a competency test.

The Secretary would be directed to conduct validation surveys of a representative sample of habilitation facilities. If he found, as a result of such validation surveys, that a state had failed to adequately perform its survey functions, the Secretary would be empowered to proportionately reduce a state's Medicaid reimbursement by one-third for the particular quarter in which the survey deficiencies occurred.

The Secretary also would be authorized to conduct special surveys where he had reason to believe that facilities were not complying with federal statutory standards for habilitation facilities.

States would be required to investigate complaints and monitor the compliance of habilitation facilities with federal certification standards.

Each state and the Secretary would be required to disclose certain information regarding the compliance of habilitation facilities with federal certification standards.

A state would be required to notify parents of any habilitation facilities found to be providing substandard services.

The survey and certification provisions contained in the draft bill parallel, almost exactly, the provisions affecting nursing facilities that are now included in Section 1919 of the Act, as a result of the passage of OBRA-87.

5. Enforcement Process

Section 203 of the Waxman bill would spell out, in statute, the actions a state would be required to take when it found a habilitation facility out of compliance with the statutory certification standards outlined above, as well as the steps a state would be expected to take to remedy the situation. Again, these provisions closely parallel the requirements of Section 1919(h) of the Act (applicable to Medicaid-certified nursing facilities).

The bill also would transfer to the Secretary responsibility for enforcing standards and imposing penalties in state-operated habilitation facilities. In addition, the Secretary would be authorized to terminate any privately operated habilitation facility (and take other steps to remedy the situation), if he found that the health and welfare of the residents of such facility were in immediate jeopardy or the facility had other persistent deficiencies.

The Secretary would be authorized to take the following steps to remedy deficiencies in habilitation facilities that were identified as part of a validation survey: (a) deny Medicaid payments; (b) impose civil monetary penalties; and (c) appoint a temporary manager of the facility. In addition, the Secretary could authorize continued Medicaid payments for up to six months during the period of correction if: (a) the state survey agency found that such actions were preferable to termination; (b) the state submitted an acceptable correction plan; and (c) the state agreed to repay the federal government if corrective actions were not taken in accordance with the approved plan of correction.

6. Reduction Plans

Section 203 of H.R. 5233 also would authorize the states to submit a reduction plan when a habilitation (ICF/MR) facility was found out of compliance with federal certification standards due to physical plant deficiencies. The conditions under which such plans could be submitted generally parallel existing requirements for ICF/MR phase down plans under Section 1922 of the Act. [N.B., The existing authority, added by Section 9516 of COBRA, would be simultaneously repealed.] The differences between Section 9516 and the proposed provisions are as follows: (a) reduction plans would only be authorized when the cause of the deficiency was related to the physical plant (i.e., not both the physical plant and staffing, as specified under current law); (b) states would be required to meet a more rigorous set of employee protections (see discussion of Title V below); and (c) reduction plans would be authorized based on findings by the state survey agency, as well as by a federal survey team.

7. Other Provisions

The revised survey and certification process outlined in Section 202 of the bill would be effective October 1, 1989. Revised utilization review/inspection of care provisions under Section 203 of the bill would be effective upon date of enactment. Any reference to a habilitation facility would be deemed to be a reference to an ICF/MR, with respect to services furnished prior to October 1, 1989.

Finally, the Secretary would be required to report annually to Congress on the extent to which habilitation facilities were complying with federal statutory certification requirements. He would be obligated to include in this report the number and types of enforcement actions taken by the states and the Department with regard to Medicaid-certified habilitation facilities.

8. State Preadmission Screening and Annual Client Review Requirements

Title HI (Section 301) of the Waxman bill would require a state, as a condition of approval of its Medicaid plan on or after October 1, 1989, to have in effect a preadmission screening program for mentally retarded individuals (and individuals with related conditions) who are admitted to habilitation (ICF/MR) facilities. In addition, states would be required to review each resident of a habilitation (ICF/MR) facility and determine whether he/she needs ICF/MR level of care and whether he/she needs community habilitation services. These reviews would have to be based on an "independent evaluation" of the person's service needs. All such initial reviews would have to be completed by October 1, 1990 and repeated annually thereafter. States would be obligated by October 1, 1989, to take the following steps with respect to persons found to be inappropriately placed in habilitation (ICF/MR) facilities:

For persons needing active treatment — consult with the family, arrange for discharge; and provide active treatment in an alternative setting;

For persons not requiring active treatment ~ discharge such individuals after orientation.

After July 1, 1989, states would be denied reimbursement on behalf of any resident of a habilitation (ICF/MR) facility who had not been prescreened prior to admission. In addition, a state would be required to establish an appeals process for use by any individual who felt he or she was adversely affected by screening/resident review determinations.

States also would be required, as a condition of approval of a state Medicaid plan, to establish an appeal process for transfer/discharge from habilitation (ICF/MR) facilities. This process would have to conform to Secretarial guidelines.

Finally, under Section 301 of the bill, the Secretary of HHS would be directed to develop criteria governing the appropriateness of serving MR/DD persons in habilitation (ICF/MR) facilities, as well as criteria governing individual appeals of preadmission screening and resident review determinations. The Secretary also would be charged with monitoring the state's compliance with the requirement that active treatment be furnished to persons found to be inappropriately placed in habilitation (ICF/MR) facilities and transferred to other settings.

9. Utilization Review

Existing utilization review and inspection of care requirements, currently contained in Section 1902(a)(26) and (31) of the Social Security Act, would be repealed under the provisions of Section 302 of the bill, along with requirements governing a physician's annual certification of continued level of care need under Section 1902(a)(44) of the Act, as they apply to habilitation (ICF/MR) facilities. This provision would become effective once the Secretary had determined that a given state was conducting annual surveys in accordance with the requirements of Section 202 of the bill (see discussion above). These new requirements would be effective on October 1, 1989.

10. Payment for Services

Title IV of the bill would amend Section 1902(a)(13) of the Act to add specific provisions governing Medicaid payments for community habilitation facility services. These parallel provisions are patterned after existing statutory language governing payments to all other Medicaid institutional providers (e.g., hospitals, nursing facilities, etc.); it would obligate a state to establish payment rates which are "...reasonable and adequate to meet the cost of providing services in conformity with

applicable State and Federal laws, regulations and quality and safety standards..." These provisions would be effective as of the start of the first quarter following the date of enactment, in the case of habilitation facilities, and as of October 1, 1989, in the case of community habilitation services.

Title IV also would prohibit the Secretary from limiting the amount of federal financial participation received by a provider of habilitation facility services or community habilitation services, by decoupling payments for such services from the so-called "Medicare upper limit". Current HHS/HCFA regulations require a state to limit payments to all providers of Medicaid-reimbursable long term care services (including ICF/MRs) to the amount the facility otherwise would be qualified to receive under the Medicare program. This amendment would be effective retroactive to the enactment date of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35).

11. Employee Protections

As a condition of approval of a reduction plan (as discussed above) or authority to amend its state plan to cover optional community habilitation services, a state under Title V of the bill, would be required to provide assurances satisfactory to the Secretary that "fair and equitable" provisions would be made to protect the interests of employees affected by the reduction plan or the provision of optional habilitation services under the state's Medicaid plan. The Secretary would be prohibited from approving either a reduction plan or the optional state plan coverage unless a state had an approved employee protection plan in place. The employee protections that would have to be specified in the plan would include:

preserving the "rights, privileges and benefits of employees" under existing collective bargaining agreements (including the continuation of pension rights and benefits);

the continuation of collective bargaining rights;

the protection of individual employees against a worsening of their job situation/position;

assurances of employment for affected habilitation facility employees, including the maintenance of pay levels and job responsibilities;

paid training/retraining programs to qualify such employees for community services jobs where a state elects to cover optional community habilitation services under its state Medicaid plan; [N.B., The cost of such training/retraining programs would qualify for federal Medicaid reimbursement.]

a grievance procedure which includes: (a) a 60 day period for informal resolution of the grievance, followed by, (b) authority for an employee to elect to either submit his/her case to binding arbitration or a hearing before a state agency.

These amendments would take effect as of the enactment date of the legislation.

12. Performance of Certain Medicaid Administrative Functions by State Developmental Disabilities Agencies

Section 502 of the bill would explicitly permit a state, under its Medicaid plan, to assign to the state MR/DD agency Title XIX administrative functions related to the provision of services on behalf of persons with developmental disabilities. This section also would explicitly authorize federal Medicaid reimbursement (at the 50%

matching level) for administrative costs incurred by a state MR/DD agency in carrying out functions under the state Title XIX plan. Both provisions would be effective as of the date of enactment.

C. Commentary on H.R. 5233

Compared to the Chafee/Florio bill, H.R.5233 represents a substantially different approach to reformulating Medicaid policies as they affect persons with developmental disabilities. The portions of Mr. Waxman's bill that address community-based services are relatively terse and, clearly, less ideologically directed than the Chafee/Florio legislation. In Representative Waxman's view, the pathway toward "incremental reform" is to grant states the option to cover community-based services rather than mandating that they do so within the context of the more prescriptive framework proposed in the Chafee/Florio legislation. In addition, most of the text of H.R.5233 is devoted to the addition of a detailed set of statutory requirements and oversight procedures governing the delivery of ICF/MR services, a topic the Chafee/Florio legislation barely touches upon. In addition, H.R. 5233 contains no provision for a "freeze" on federal payments to larger ICF/MRs, reflecting Representative Waxman's adamant opposition to the introduction of any such reimbursement limitations in Medicaid statutes.

Before commenting on some of the specific provisions of the legislation, it may be helpful to point out that the approach used in drafting H.R.5233's ICF/MR provisions represented an attempt to restructure Title XIX statutes governing the ICF/MR program in a manner which closely parallels the nursing home reform provisions adopted by Congress in 1987 (P.L. 100-203). These provisions reflect the view that only reliable way of assuring effective federal and state enforcement of the basic requirements governing participation in the Medicaid program is statutory law. In addition, the regulatory mechanisms and resident assessment provisions of the legislation also reflect the view that existing mechanisms (such as inspection of care) have proved to be ineffective in assuring that high quality services are furnished to residents of Medicaid-certified facilities and that only persons who require ICF/MR level of care are served in such facilities. The ICF/MR program had been specifically excluded when Congress rewrote Title XIX statutes governing long-term care facilities in an effort to improve federal and state oversight of nursing facility operations. Thus, a significant portion of H.R.5233 is intended to create an approach to regulatory ICF/MRs that parallels the new Congressional requirements governing the operation of Medicaid-certified nursing facilities.

Given the fact that the Waxman bill was only recently introduced and thus has not been the subject of extended commentary, as has the Chafee/Florio legislation, the relatively detailed comments below are intended not only to discuss the relationship of key provisions of the bill to the broader issues surrounding the Medicaid reform agenda, but also to identify the basis and potential ramifications of key provisions that are less directly tied to such issues. The commentary that follows parallels the five major sections of H.R.5233:

1. Optional Expansion of Community-Based Services (Title 1)

Section 101 of H.R. 5233 potentially could represent a major step toward rectifying the current institutional bias of Medicaid policy. By establishing a regular state Medicaid plan option as an avenue through which states could claim Title XIX reimbursement for a wide range of community habilitation services, Congress would be giving the states substantial authority to equalize federal financial incentives to support institutional and community-based service options under their Medicaid programs. Certainly, from the perspective of state mental retardation/developmental disabilities agencies, authority to cover a broad array of community services under a state plan option would be far superior to providing such services as part of a HCB waiver, since states would be able to avoid: (a) the disruptive aspects of HCFA's management of the HCB waiver program; and (b) the utilization and expenditure limitations associated with the waiver authority, thus allowing them to extend community-based services to additional recipients.

A proposal to expand coverage of community-based services through the authorization of an optional state plan coverage, however, falls far short of achieving the objectives of assuring a minimum nationwide floor of eligibility and the availability of a given range of mandatory services. Under the optional state plan approach, any state would be free to elect or reject the coverages that would be permitted under H.R.5233. In addition, an optional state plan coverage also gives a state the authority to impose limits on the duration, frequency, and scope of covered services and, hence, to restrict the utility of such services in meeting the needs of the defined service population.

There, however, are several advantages to the optional state plan approach. First, as discussed in Chapter II of this report, this approach comports with the approach Congress has used historically in modifying the Medicaid program. Only rarely have states been mandated to furnish certain services or to cover certain groups of individuals; instead, Congress has afforded states the option of broadening their Medicaid programs in discrete ways. Second, state policymakers are quick to object when Congress proposes a measure that would force a state to increase its own outlays. Third, as will be pointed out in the next subsection, an optional state plan approach is generally viewed as having decidedly lower impact on future Medicaid outlays for community-based services than the approach outlined in the Chafee/Florio legislation. To the extent, therefore, the prospects of any Medicaid reform proposal is tied to its likely budgetary impacts, an optional service approach can be expected to have more favorable prospects of enactment.

The basic tenor of the definition of community habilitation services contained in H.R.5233 is very similar to the majority of services that states are presently furnishing under HCB waiver programs. Since nearly eighty per cent of all states have such programs in operation, it is likely that states could rapidly operationalize the coverage that has been proposed by Representative Waxman. Indeed, it is not far-fetched to suggest that H.R. 5233 would represent the conversion of the HCB waiver authority into a state plan service. Some observers, however, have pointed out that it would be difficult to employ a habilitation plan coverage to infuse Medicaid dollars into family support services and other services without direct client training objectives.

The potential benefits of this proposed optional state plan coverage, however, could prove to be little more than an empty promise unless some of the conditions that would be attached to the inclusion of community habilitation services under a state's Medicaid plan were substantially modified. Among the current features of H.R. 5233, as introduced, that would prove potentially problematic to a state that elected to add community habilitation services as an optional coverage to its Medicaid state plan are:

- a. **Employee Protections.** States would be obligated, as a condition of covering such services under their Title XIX plan, to provide assurances that certain explicit job protections would be afforded to current employees whose jobs would be affected by such coverage. Leaving aside for the moment the reasonableness of the proposed job protections themselves (see discussion below), there are several reasons why such safeguards could prove problematic.

First, the provision assumes a direct, cause-and-effect relationship between the provision of Medicaid-reimbursable community services and threats to the job security of present employees. More than three-quarters of the states, however, have established and operated Medicaid HCB waiver programs over the past eight years without any demonstrable evidence of broad-scaled lay-offs or job termination actions involving employees of public mental retardation institutions. To make job protections a condition of covering "community habilitation services", therefore, would be perceived by states as simply a backdoor means of assuring preferential treatment for

one segment of the work force in qualifying for newly established community positions.

Second, the proposed employee protections could add significantly to the cost of delivering community-based services without necessarily yielding demonstrable improvements in the quality and accessibility of services available to persons with developmental disabilities. One possible aim of the proposed employee protections is to force states and counties to directly operate community day and residential services for persons with developmental disabilities. This of course, is an option currently available to the states, although to date only a relatively few states have elected to emphasize public operation of community programs and facilities and, even in these states, often there is a combination of public and private service provision. States have chosen to use primarily private provider agencies for a variety reasons, many of which have to do with historical factors surrounding the initiation and expansion of such services in the particular state. There is little doubt, however, that the generally higher cost associated with employing unionized public workers has served as a disincentive to the establishment of state and county operated community programs/facilities. To the extent, therefore, that the proposed employee protections would result in an increase in publicly operated community programs, a significant increase in the marginal cost (30 to 40 percent in some states) of providing such services might be anticipated.

The inadequate salaries of community service workers unquestionably pose a major problem in many states. In fact a growing number of states have launched initiatives to increase the pay of such workers over the past few years in an effort to assist provider agencies in coping with the problem of employee turnover. Nonetheless, one near term potential impact of expanded public operation of community services would be additional Medicaid costs without any assurance of improvements in the quality of such services.

b. Federal Standard Setting Authority. In order to qualify for Medicaid reimbursement, a provider of community habilitation services in a supervised residential setting would have to meet standards promulgated by the Secretary of HHS. The introduction of uniform federal standards governing the operation of Medicaid-supported community residences would have far-reaching ramifications. Recent experience with federal standard setting in the area of ICF/MR policy strongly suggests that the application of federal standards would result in: (a) a monolithic nationwide approach to delivering community residential services at a time when the emphasis in the field has shifted to creating a wider array of more individualized living and programming arrangements; and (b) a clinically-driven model of services that ultimately would increase the cost of operating Medicaid-funded residential programs substantially without necessarily achieving any measurable improvements in the quality and appropriateness of services provided to residents.

Over three-quarters of the states have regulated Medicaid financed HCB waiver services in community residential settings over the past eight years without any major indications that federal standards are necessary. Indeed, the flexibility to tailor minimum operating standards to the needs of particular types of residents and the nature of the residential environment has been one of the principle advantages of the HCB waiver programs. A number of states have taken advantage of this flexibility to design new, more effective and normalizing living arrangements for waiver participants in recent years - a step that simply would not be possible if uniform federal standards were to be imposed.

The issue of the federal role in setting and enforcing standards for community-based services is likely to represent a significant point of contention in the future consideration of this legislation. At heart, the issues in this area involve very thorny questions of the proper locus of accountability for assuring the quality of services purchased in part with federal dollars. There is no doubt that Congressional concerns regarding the lack of vigor that marked both state and federal oversight of nursing facilities has created a resolve to assure that HCFA plays a forceful role in overseeing the quality of all Medicaid-financed services. Congressional perceptions that states have not done a good job in enforcing ICF/MR standards also play a role in the desire to assign substantial oversight authority and responsibility to the Secretary.

Against this backdrop of federal concerns, however, stands the enormous mistrust and dissatisfaction with HCFA's regulatory initiatives in the area of ICF/MR services. On the whole, states view the prospect of an expanded role for HCFA as extremely threatening and ultimately counterproductive to their efforts to expand and enhance community-based services.

Linkage to Institutional Need. H.R. 5233 would establish a two-tiered system of eligibility for Medicaid-reimbursable community habilitation services. Categorically eligible recipients of Medicaid (generally those who are eligible for SSI or AFDC cash payments) would be entitled to receive optional community habilitation services if a state elected to cover this service under its Medicaid plan. States also could choose to cover an optional categorically eligible group of recipients, consisting of non-Medicaid eligible individuals who would be eligible for Title XIX services if they were residing in a Medicaid-certified institution and who, in the absence of the community habilitation services they need, would require the level of care provided by a ICF/MR.

It is important to note that H.R. 5233 does not directly link eligibility for "community habilitation services" to an "institutional needs" test in the case of categorically eligible Medicaid recipients, as it does in the case of the optional categorically eligible group. Indeed, the language of Section 101(b) of the bill states that such services may be furnished "... without regard to whether or not individuals who receive such services have been discharged from a nursing facility or habilitation [ICF/MR] facility." However, the intent of the drafter of the legislation is not entirely clear in this respect.

It is clear, however, that the extent to which eligibility for community habilitation services is conditioned on the need for institutional (ICF/MR) services makes an enormous difference - particularly whether this test is applied to categorically eligible Medicaid recipients. If all recipients of community habilitation services were required to need ICF/MR level of care, the proposed optional service coverage would have few advantages over the existing HCB waiver authority, as a vehicle for claiming Medicaid reimbursement on behalf of community clients, since, arguably, the door would be open for HCFA to exercise the same types of constraints on utilization and expenditure levels as it currently imposes under the HCB waiver program (e.g., regulating the total number of ICF/MR plus waiver recipients according to the states aggregate ICF/MR bed capacity).

In fact, HCFA's control over a state's utilization of community-based services could be even further strengthened under the proposed legislation, since under Title m of H.R. 5233 the Secretary of Health and Human Services would be authorized to establish national criteria governing admission to, and continued stays in, ICF/MRs (see further discussion below). Anytime, therefore, the Secretary elected to tighten ICF/MR

eligibility criteria, he would automatically constrain the types and numbers of persons a state could find qualified for Medicaid-reimbursable community habilitation services, since the state would have to make a determination that potential recipients of such services otherwise would require habilitation facility (ICF/MR) level of care.

These provisions regarding the "need for institutionalization" test are viewed by many observers as potentially embedding further in Medicaid statute an irrational means of targeting Medicaid reimbursable services to persons with developmental disabilities. It should be pointed out, however, that CBO estimates of the fiscal impact of the legislation are strongly influenced by the perception that this test will contain the potential increase in Medicaid outlays that might be triggered by the legislation.

Scope of Reimbursable Services. The definition of the term "community habilitation services" that is included in Section 101 (a) of the Waxman bill is a modification of the current definition of "habilitation services" that appears in Section 1915 (c)(5) of the Social Security Act (i.e., the statutory authority for the Medicaid home and community-based waiver program). The major differences between the existing statutory definition and the one contained in H.R. 5233 are: (a) the word "community" would be added and the types of coverable services would be limited explicitly to those "...which assist individuals in participating in community or other activities"; (b) reimbursement for residential habilitation services would be linked to compliance with federal standards (as discussed above); and (c) non-reimbursable room and board costs would be explicitly delimited in the definition.

To date, HCFA generally has given the states rather broad latitude in defining the elements of services that are Medicaid reimbursable as habilitation services under a home and community-based waiver. Were this practice to continue under the proposed optional state plan service, states would be in a position to recover a significant portion of community service costs on behalf of Medicaid-eligible recipients, especially if they were to combine the optional community habilitation services coverage with the optional targeted case management coverage available under Section 1915(g) of the Act.

If, on the other hand, HCFA were to construe more narrowly the elements of a typical day or residential service that were claimable under this proposed new Medicaid service rubric, states could find that only a small fraction of total program costs qualified for Medicaid reimbursement. The inclusion of an explicit delineation of non-reimbursable room and board costs eliminates (or at least narrows) one device that could be used to limit federal financial participation in the cost of community residential services, but it hardly exhausts all of the possible avenues to narrow the scope of federally reimbursed elements of habilitation services.

Section 102 of H.R. 5233, as mentioned earlier, would eliminate the current restriction on the application of the broader definition of habilitation services that was added to the Act in 1986. Under COBRA-85, states were permitted to claim reimbursement for supported employment, prevocational and educational services under a HCB waiver, as long as such services were not otherwise fundable under the Education of the Handicapped and Vocational Rehabilitation Acts; however, these additional types of habilitation services may be claimed only on behalf of former institutional residents. Section 102 would expand eligibility for the broader range of habilitation services under HCB waiver programs to all waiver recipients.

; Section 103 of H.R. 5233, as mentioned earlier, would require the Secretary to develop, through demonstration projects and contracts, outcome-oriented instruments/methods of evaluating the quality of Medicaid-supported community habilitation services. The deadline for completing work on these instruments/methods would be January 1, 1991. In order to qualify for continued Medicaid support of community habilitation services, a state would be required to use the instruments and methods developed by the Secretary, after July 1, 1991, in evaluating such services and to discontinue payments to any provider found to be furnishing sub-standard services. This requirement would apply to community habilitation services reimbursed under a HCB waiver as well as under the proposed new optional state plan coverage.

The concept of granting the Secretary explicit statutory authority to support research and demonstration projects to develop outcome oriented assessment techniques is, no doubt, a worthwhile step. On the other hand, given the fact that the state-of-the-art in the development and use of outcome measures is still in its infancy, it may be premature to set a specific statutory deadline for implementing such assessment instruments/methods on a nationwide basis.

Quality Assurance for Habilitation Facility Services (Title II)

As noted earlier, H.R. 5233 contains an extensive set of statutory provisions regarding ICF/MR services (renamed "habilitation facilities" in the bill). This detailed attempt to revamp federal statutes governing the ICF/MR program contrasts sharply with the Chafee/Florio legislation which focuses almost exclusively on provisions to establish community-based services as a viable substitute for, or complement to, the ICF/MR program. Again, it is important to note that the provisions contained in H.R. 5233 concerning habilitation facilities have been strongly influenced by Congress would experience in attempting to create a sounder basis for regulating nursing facilities. While many would argue that the problems that led to the passage of the "nursing home reform" provisions of the Omnibus Budget Reconciliation Act of 1987 are quite different from those being experienced in the ICF/MR program. H.R. 5233's ICF/MR related provisions are based on the notion that the structural changes in nursing facility services represent a generalizable regulatory structure that should be extended to the ICF/MR program.

It also is useful to emphasize that in the arena of the regulation of nursing facilities, Congress was led to conclude that HCFA should play a proactive role in the regulatory process; inadequacy in state oversight efforts was viewed as a key factor in permitting the continued provision of low quality services in many nursing homes. At the same time, however, Congress was fearful that HCFA, left to its own devices, would not vigorously enforce regulations or establish appropriate standards. Thus, Congress included detailed operating standards in OBRA-87 and attempted to create a framework in which HCFA would be required to play an active role in program oversight. Despite reservations concerning the agency's past performance, Congress concluded that it would be preferable to grant HCFA expanded authority rather than leaving enforcement of nursing home standards entirely to the states.

Hence, H.R. 5233's provisions regarding the regulation of ICF/MRs were framed against the backdrop of recent Congressional actions to improve the quality of nursing facility services. As a consequence, the bill would enact highly detailed service delivery standards and give to the Secretary of HHS significant authority to regulate the appropriateness of placements in ICF/MRs.

Among the other specific provisions of Title II of H.R. 5233 that merit comment are:

- a. **Requirements Applicable to Habilitation Facilities.** Section 201 of the draft bill would incorporate in federal statute detailed operating standards

applicable to "habilitation facilities" (currently referred to as ICF/MRs). The general format and some of the specific contents of these standards closely parallel the provisions of Section 1919(a) through (d) of the Act (applicable to nursing facilities), as added by the Omnibus Budget Reconciliation Act of 1987 (OBRA-87; PI* 100-203). These nursing facility "conditions of participation" have been modified to include key provisions of the revised ICF/MR regulatory standards, published by HHS's Health Care Financing Administration (HCFA) on June 3, 1988.

Leaving aside the detailed language of Section 201 of the bill, the overriding questions that must be answered are: (a) does it make sense to, in effect, transfer existing regulatory "conditions of participation" to federal statute; (b) if so, do the conditions as drafted provide a reasonable basis for assessing the compliance of habilitation (ICF/MR) facilities; and (c) would the addition of statutory standards increase or decrease the vulnerability of states to adverse compliance actions in ICF/MR-certified facilities?

The conditions, as drafted, are not entirely consistent with HCFA's new ICF/MR regulations, since, as noted above, to a considerable extent the "generic" provisions are taken, practically verbatim, from the nursing facility conditions of participation enacted last year as part of the 1987 reconciliation legislation (P.L. 100-203). The extent to which these dissimilarities are likely to create significant problems for current and future providers of ICF/MR services is a matter of debate.

- b. Survey and Certification Process. Section 202 of the bill would add new statutory requirements governing the conduct of surveys and certification of habilitation facilities. In addition, it would transfer responsibility for surveying and certifying state-operated habilitation (ICF/MR) facilities from the state survey agency to the Secretary. These requirements are identical, in most respects, to the provisions of Section 1919(g) of the Act (applicable to nursing facilities), as added by OBRA-87.

Here again, the key question is the extent to which survey and certification requirements that were originally designed for nursing facilities can be applied to habilitation (ICF/MR) facilities without generating new problems for the states and facility operators. Of particular note is the proposed transfer of survey and certification authority to HHS/HCFA in the case of state-operated habilitation (ICF/MR) facilities. On the one hand, such a transfer would further strengthen HCFA's already extensive control over the operation of public ICF/MR facilities. On the other hand, some directors of state facilities, as well as some state MR/DD agencies, will argue that since HCFA already exercises *de facto* control over the certification of such facilities, it would be preferable to eliminate state survey agencies from the survey/certification loop, so that facilities were subject to only one set of surveys.

- c. Enforcement Process. Section 203 of the Waxman bill would spell out, in statute, the actions a state would be required to take when it found a habilitation facility out of compliance with the statutory certification standards outlined above, as well as the steps a state would be expected to take to remedy the situation. Again, these provisions closely parallel the requirements of Section 1919(h) of the Act (applicable to Medicaid-certified nursing facilities).

The bill also would transfer to the Secretary responsibility for enforcing standards and imposing penalties in state-operated habilitation facilities. In addition, the Secretary would be authorized to terminate any privately operated habilitation facility (and take other steps to remedy the situation),

if the health and welfare of the residents of such facility were found to be in immediate jeopardy or the facility had other persistent deficiencies.

Here again, the most critical issue is the proposed transfer of direct authority to impose sanctions in state-operated ICF/MRs to the Secretary. The same questions outlined above in the case of the proposed transfer of survey and certification authority apply in the case of enforcement.

- d. Other Key Issues. In certain respects, the provisions of Title II of H.R.5233 fall outside the commonly accepted framework of concerns that must be addressed in efforts to reformulate Medicaid policies. It is difficult to argue, for example, that including current ICF/MR regulations in statute will have a substantial, immediate impact on facilities, since they are already subject to similar requirements under HCFA promulgated regulations. Similarly, the proposed Secretarial authority to regulate state-run facilities would not represent a dramatic departure from present circumstances where the "look-behind" survey authority gives the Secretary the discretion to do exercise de-facto control over such facilities.

At the same time, many observers consider it ill-advised to view federal ICF/MR regulations as a basis for describing what may constitute "high quality" services. Unlike the standards that Congress adopted for nursing facilities, the present ICF/MR standards have never been carefully scrutinized to determine their effectiveness in promoting the stated objectives of the program.

Some would argue that certain standards are counterproductive in promoting the independence and self-sufficiency of facility residents. The rising "threshold of compliance" and its implications for the costs of furnishing ICF/MR services are a cause of enormous concern. Thus, it seems reasonable to question whether freezing the current regulatory framework in place represents a wise step and whether it might not be more appropriate for Congress to mandate an in-depth study of the ICF/MR program similar to the one that preceded the adoption of the nursing facility standards. More globally, the question is whether freezing current regulations in place would place the states in an uncomfortable fiscal dilemma regarding whether scarce dollars, where they either had to allocate the limit available to maintain current ICF/MR facilities or expand community-based services.

Appropriate Placement for Mentally Retarded Individuals (Title 111)

Another area addressed in the Waxman legislation but not addressed in the Chafee/Florio bill is the establishment of national criteria governing the determination of the appropriateness of ICF/MR placements. Present policies leave it to the states to define "level of care" criteria governing admissions to and contained stays in ICF/MRs.

Under H.R.5233, the Secretary of HHS would be empowered to establish ICF/MR placement/continued stay criteria that would have to be followed by all states. These provisions are described in detail above and are patterned after the nursing facility preadmission screening and resident review requirements that were incorporated in OBRA-87. Basically, these provisions make little sense in the context of the present legislation since they would direct the states to determine (and re-determine annually thereafter) whether existing residents of ICF/MR facilities need active treatment and, if they do, to transfer then to a facility in which they could receive such services. But, the legislation constitutes something of a non-

sequitor since, by definition, the only setting in which active treatment can be provided is an ICF/MR.

Viewed more broadly, however, Section 103 poses another and more troubling question: should there be national standards of eligibility governing admission to, and continued stays in, ICF/MR facilities. Currently, each state, by and large, establishes its own, individual criteria of eligibility for ICF/MR services. What Title III of H.R. 5233 portends is the exercise of closer federal scrutiny over who gets admitted to and stays in ICF/MR facilities.

The potentially disturbing aspect of such a delegation of authority is that it would give the Secretary sweeping powers to tighten ICF/MR eligibility criteria and thereby limit the number and types of persons eligible to receive such services at a time when HCFA places high priority on containing the growth of federal Medicaid costs. As noted above, not only would the Secretary have authority to restrict participation in the ICF/MR program, but he would also be able to limit participation in HCB waiver programs and in programs financed through the proposed optional habilitation state plan service.

The premise undergirding these provisions of H.R.5233 is that ICF/MR services ought to be restricted to those individuals for whom they represent the most appropriate, necessary means to meet their active treatment needs. The difficulties posed by this premise are several-fold. First, it presupposes a readily measurable threshold of need that, in fact, never has been operationalized for the ICF/MR program. Second, it assumes that active treatment services themselves are clearly defined, an assumption with which many would disagree. Third, for many critics of the ICF/MR program, it would validate placement in a residential setting that they view as overly restrictive. Again, critics of this approach note the approach proposed in Section 301 of H.R.5233 assumes that the Secretary can provide a clear set of criteria, rather than establishing a carefully thought out process to determine the potential pros and cons of various criteria and their possible implications for the service delivery system.

Payment for Community Habilitation Services and Habilitation Facility Services (Title IV)

The provisions regarding payment for community habilitation and ICF/MR services in H.R. 5233 essentially transfer the provisions of the present day "Boren Amendment" standard, which obligates a state to establish payment rates which are "...reasonable and adequate to meet the cost of providing services in conformity with applicable State and Federal laws, regulations and quality and safety standards..." to community habilitation services, while at the same time attempting to countermand regulations that HCFA finalized in July 1987 to test the allowability of state payments for ICF/MRs against the so-called "Medicare upper limit."

With regard to placing payments for community habilitation services within the parameters of the Boren Amendment, it should be noted that provider agencies, in particular, do not view the Boren Amendment as a sufficient assurance that the states will establish payment levels that are adequate or which encourage the provision of high quality services. The Boren Amendment was adopted in 1981 to grant states a tool to implement long-term care reimbursement systems that were more amenable to cost containment efforts. Provider agencies, however, argue that one result has been to permit states to hold down payment rates to levels that force such agencies to pay substandard wages to community workers and compromise the quality of services to the individuals they serve. As a consequence, such organizations have argued that affirmative statutory requirements are needed to assure that payment rates are sufficient to permit provider agencies to pay competitive wages and comply with applicable federal and state standards.

The "Medicare upper limit test" that HCFA established in 1987 as a test of the allowability of state claims for Medicaid reimbursement for ICF/MR and other long term care services constitutes, in the view of Representative Waxman, yet another attempt by HCFA to administratively impose a cap on the Medicaid program. While the upper limit test is extremely complex, one potential outgrowth is that a portion of state payments for ICF/MR services might be subject to federal disallowance based on the application of independent federal tests of what constitutes a reasonable payment level. If state payments, for whatever reason, increased more rapidly than the rate of general economic inflation, for example, a state may face a disallowance, even if the payment increase were prompted by provider agency responses to state or federal survey actions. It might be noted that Representative Waxman has attempted in the past to prohibit the Secretary from imposing this test, only to be rebuffed by the Senate which has been swayed by Administration contentions that the result would be a significant increase in federal outlays.

5. Employee Protections and Miscellaneous Provisions (Title V)

- a. Employee Protections. While the Chafee/Florio legislation contains provisions regarding the protection of employees who might be adversely affected by decisions to reduce the scope of operations in state-run facilities, H.R.5233's provisions are far more sweeping and potentially troublesome to state policymakers. For example, some state officials have commented that the provisions might entail bringing the Secretary of HHS to the table in order to negotiate collective bargaining arrangements.

While assisting public employees who are adversely affected by a decision to reduce the population or close a public ICF/MR facility to find new employment is viewed by most supporters of Medicaid reform legislation as a fair proposition, the provisions of H.R.5233 strike many as stepping beyond the bounds of employee protection to guarantee job security, in perpetuity. At the same time, however, it must be recognized that the Democratic leadership of the House of Representatives traditionally has viewed job protections as a key objective, and, hence it seems unlikely that DD Medicaid reform legislation would be reported out of the House Energy and Commerce Committee without at least some employee protection provisions. The questions evoked by H.R. 5233 is what constitutes a reasonably balanced approach to such protections that would not hold the use of Medicaid funds for community services hostage to the job security of unionized employees.

- b. Performance of Certain Medicaid Administrative Functions by State Developmental Disabilities Agencies. It should be noted that Section 502 of the bill roughly parallels comparable provisions in the Chafee/Florio legislation, by explicitly permit a state, under its Medicaid plan, to assign to the state MR/DD agency Title XIX administrative functions related to the provisions of services on behalf of persons with developmental disabilities. H.R. 5233, however, differs from the Chafee/Florio bill in that it would not mandate the consolidation of federal administrative responsibilities within a newly created bureau of HCFA.

7. Conclusion

H.R. 5233, then, differs in many important respects from the Chafee/Florio legislation. It is fair to say that with respect to fashioning changes in present policies to permit broader utilization of Medicaid dollars to support community-based services that the Waxman bill is indeed more "incrementalist" than the Chafee/Florio legislation. It also presumes a more intrusive role for the federal government in the management of Medicaid-financed developmental disabilities

services than S.1673/H.R.3454. A very firm quid pro quo of increased oversight in exchange for increased funding was put on the table by H.R. 5233.

There seems little doubt that, from the perspective of the states, evaluating the relative merits of this proposed trade-off is clouded by the adversarial relations that have marked federal-state interactions around Medicaid funding of developmental disabilities services over the past five years, as well as growing frustration with the directions that HCFA has taken in the regulation of the ICF/MR program. For other stakeholders in the Medicaid reform debate, H.R.5233 appears to be "half-a-loaf" because it is not framed as a strong entitlement to community services. However, given Representative Waxman's position in the House and his role in defining national Medicaid policies, achieving acceptable compromises between H.R.5233 and S.1673/H.R.3454 in the 101st Congress could prove to be difficult.

D. Estimated Fiscal Impact of H.R.5233

In conjunction with its formal budgetary impact statement on S.1673/H.R.3454, the Congressional Budget Office developed fiscal impact projections on H.R.5233. The magnitude of these projections was substantially less than the cost estimates for the Chafee/Florio legislation. In the context of the federal budget, CBO's H.R.5233 projections could be characterized as "decimal dust" ~ i.e., of such small magnitude that it is not serious concern in the debate concerning reducing the federal deficit.

More specifically, the table below lays out CBO's projections for H.R.5233 to cover the first five years after enactment:

H.R. 5233 ESTIMATED FEDERAL COSTS (millions of dollars) Table 2					
	1989	1990	1991	1992	1993
Increase in Recipients and Costs: Community Services	0	25	25	30	35
Limitation on Payments to Institutions	0	0	0	0	0
Administrative Costs	1	6	7	10	13
TOTAL	1	31	32	40	48
Source: CBO, 1988					

Since H.R.5233 would not establish a freeze on payments to larger ICF/MRs, the reduction in federal outlays stemming from that provision of the Chafee/Florio legislation obviously is not a factor in CBO's projections of the potential fiscal impacts of H.R.5233. Beyond this difference, the projected additional federal outlays for community-based services is substantially less than projected for Chafee/Florio bill. In FY 1992, for example, CBO's estimates that the impact on Medicaid outlays for this element of the Chafee/Florio legislation would be \$750 million versus \$30 million for H.R.5233.

In deriving its impact of H.R.5233 on federal payments for community-based services, the CBO analysis took into account the following factors:

First, CBO estimated that only 105,000 additional persons would become eligible under the provisions of H.R.5233. CBO's estimate was substantially influenced by its view that the "need for institutionalization" test would significantly reduce the number of potentially eligible individuals. CBO

also noted that only 30-40 percent of this group would likely receive Medicaid-financed community services by FY 1993 and state start-up of programs under this legislation would be slower than if states had been mandated to provide services to eligible individuals.

Second, CBO assumed that only 15 percent of the states would elect to cover community habilitation services under their Medicaid state plans. CBO based this estimate on experience with state utilization of recently adopted optional Title XIX coverages and its belief that states would be reluctant to select an optional state plan service to which so many strings were attached.

CBO noted that, in its view, if all states were to elect to cover community habilitation services, the price tag attached to H.R.5233 would only rise to \$220 million by FY 1993, or about 20 percent of the projected increase in outlays for community and family support services under the Chafee/Florio legislation in the same year. In addition, it might be noted that CBO estimates that the administrative costs associated with the Waxman legislation are substantially lower than the costs of the Chafee/Florio bill.

The Reagan Administration has not published its own estimates of the fiscal impact of the Chafee/Florio legislation. It might be conjectured, however, that its views of the potential impact would be substantially different than the estimate produced by CBO.

In point of fact, the potential fiscal impact of the Waxman legislation poses just as difficult projection problems as the Chafee/Florio legislation. The following factors could considerably affect any projections of the budgetary impact of the Waxman legislation:

Given the similarity of "community habilitation services" to the services furnished by states under their HCB waiver programs, it might be conjectured that many states which currently administer such programs would happily cash them in for a Medicaid state plan coverage. With such coverage, a state could avoid the problems associated with periodic renewal of its waiver program and would not face the restriction on the total number of recipients and spending that are now imposed by HCFA on HCB waiver programs. It is arguable whether the strings attached to increased funding that might be associated with the Waxman legislation would be viewed as any more onerous than HCFA's intense scrutiny of state waiver programs. In addition, it is worth noting that, should H.R. 5233 be enacted, a state which operates an HCB waiver program would be required to meet the same requirements as if it had opted to cover community habilitation services under its state Medicaid plan (e.g., federal community services standards would be applicable to both state plan services and waiver financed services).

Many would question the weight that CBO gives to the "need for institutionalization" test in an estimate of financial impact of adding community habilitation services as an optional Medicaid state plan coverage. Whether such a test would truly prove to be an impediment to making additional persons eligible for Medicaid-reimbursable community programs would depend less on the objective assessment of an individual's need than whether HCFA would seek to impose stringent conditions similar to those now employed under the HCB waiver program.

- Conceptually, the potential universe of eligible individuals with developmental disabilities is likely to be just as large under the Waxman bill as the Chafee/Florio legislation. Of course, to the extent that the Chafee/Florio legislation would reach beyond the traditional developmental disabilities population to encompass groups that experience severe disabilities later in life, it certainly would entail a broader target population than H.R.5233.

Finally, the Waxman legislation contains no "maintenance of effort" requirement and, hence, presumably would permit the states to move relatively quickly to qualify for Medicaid financing programs now funded solely from state funds.

As with the Chafee/Florio legislation, the ultimate fiscal impacts of the Waxman legislation would depend on how states reacted to the final provisions of the legislation, as they weighed options regarding the financing of community-based services.

APPENDIX C:

THE ASPE/HHS MEDICAID REFORM PROPOSAL

APPENDIX C:

THE ASPE/HHS MEDICAID REFORM PROPOSAL

A. Introduction

While largely ignored in the debate over Medicaid reform for persons with developmental disabilities is a proposal developed during 1987 by a special task force of the U.S. Department of Health and Human Services (HHS). This proposal may never emerge as a serious alternative to the Chafee/Florio or Waxman bills; however, it provides important clues regarding sentiments toward reformulating Medicaid policies within HHS.

The Department's Medicaid reform proposal has its roots in long-standing Reagan Administration concerns about the rapid growth in federal Medicaid outlays for specialized DD services. Administration representatives have frequently cited the increase in such expenditures as a major cause of burgeoning federal long-term care outlays and, consequently, as a significant contributing factor to the overall growth in Medicaid spending. While the proposal developed by the Department is based on substantive analysis of the detrimental impacts of current federal policies on the provision of specialized DD services, it is important to recognize that slowing or stabilizing the rate of growth in federal outlays for such services has long been a primary objective of the Reagan Administration.

Responsibility within HHS for analyzing the impact of current federal policies and developing policy alternatives was assigned to the Office of the Assistant Secretary for Planning and Evaluation in 1984, after Congress directed the Secretary to study the effects of Medicaid policies on the delivery of state/local services to persons with developmental disabilities. Following the submission of HHS's report to the Congress, the Secretary, at the suggestion of ASPE, formed a "Working Group" made up of representatives of various units of HHS, including the Health Care Financing Administration (HCFA), the Office of Human Development Services (OHDS), the Social Security Administration (SSA) and the Office of the Assistant Secretary of Health (OASH). In addition, ASPE commissioned several consultants to complete various studies concerning the impact of present policies as well as proposed policy changes.

The Secretary instructed the Working Group "...to analyze federal policy barriers to community living and to develop cost-effective policy options to enhance the independence, community integration and productivity of persons with mental retardation and other developmental disabilities." The working group developed draft reports containing policy proposals for circulation within HHS and the Administration. Late in 1987, the ASPE staff began meeting with various national interest groups to gauge their reaction to the tentative proposals that had been developed to date.

A draft report to the Secretary was completed in March 1988 and circulated to representatives of national organizations (ASPE/HHS, 1988). Over the summer of 1988, refinements were made in the proposed methodology for allocating payments to the states. In the fall of 1988, the Secretary of HHS incorporated ASPE's proposal as a suggested new legislative initiative in the Department's FY 1990 budget submission to the Office of Management and Budget (OMB). Ultimately, OMB decided not to include the proposal in President Reagan's final budget. At the same time, however, enthusiasm for the ASPE/HHS plan remains high within the Department and materials concerning the proposal have been provided to President-elect Bush's transition team. It is unclear, as of this writing, whether the Bush Administration will adopt the ASPE/HHS proposal as its position on reforming present federal Medicaid policies as they affect persons with developmental disabilities.

The discussion of the ASPE/HHS proposal that follows relies on a review and analysis of the draft report published in March 1988. In addition, collateral documents were used to gain further insights into how the Working Group sought to structure its final recommendations to the Secretary. At the same time, however, it must be pointed out that many elements of the draft proposal have yet to be fleshed out. Hence, discussion of the proposal is limited by the lack of precise legislative specifications or access to actual bill language.

B. Basis of the Proposal

During its deliberations, the ASPE Working Group concluded that current Medicaid policies constitute a significant barrier to the effective use of federal dollars in supporting specialized DD services. It also agreed that present Medicaid policies largely support services - principally furnished through large ICF/MRs — that are extremely costly yet contrary to commonly accepted service delivery principles, such as fostering normalization and community integration. In addition, the Working Group: (a) noted the difficulties experienced by many states in employing Medicaid funding while also sustaining a unitary approach to the overall management of a state's service delivery system (Jaskulski and Weader, 1987); and (b) questioned the compatibility of Medicaid financing of services with MR/DD community-based service delivery systems as they have evolved in the states. The ASPE Working Group also found that reliance on Medicaid financing as the principle vehicle for channeling federal assistance to the states for specialized DD programs led to problems in covering certain groups of individuals. Finally, the Working Group noted that existing policies have led to large disparities in the ways in which various states use Medicaid dollars to support specialized services and expressed concerns that this crazy-quilt pattern of utilization of federal Medicaid benefits has resulted in extremely uneven access, nationwide, to needed services by individuals with severe disabilities.

To address these issues as well as meet the Administration's overall objective of assuring that future outlays for specialized DD services be placed on a predictable course, the Working Group proposed that the use of Medicaid dollars to finance specialized DD services be terminated in favor of a new statutory authority that would utilize a formula grant mechanism (like Title XX) to distribute federal aid to the states to support specialized DD services. Under this relatively radical Medicaid reform proposal, states would be mandated to serve persons who are most severely disabled. In addition, the federal government's oversight role would be considerably restructured.

The ASPE/HHS Working Group's proposal was aimed at:

- (a) broadening the array of services for which federal financial support would be available;
- (b) eliminating detrimental Medicaid policies in order to promote greater service delivery efficiency and effectiveness;
- (c) indexing federal funding for specialized DD services to assure greater predictability in the level of federal outlays; and,
- (d) assuring that individuals with the most severe disabilities are entitled to receive a basic array of services in all states.

In the event that its primary proposal was not accepted, the ASPE Working Group also developed recommendations for changing existing Medicaid policies.

At first glance, the ASPE/HHS proposal appears to offer the states an opportunity to exchange Medicaid's open-ended funding stream, with all its related restrictions, for greater flexibility in using federal dollars to support services for persons with developmental disabilities. As such, the proposal appears, at least nominally, to be consistent with a central theme of the early years of the Reagan Administration: namely, offering the states greater

control of programs financed with federal dollars in exchange for reduced (or at least a reduced rate of growth in) federal financial assistance.

Upon closer examination, however, the plan developed by the ASPE/HHS Working Group is far more complex than a simple quid pro quo that would exchange open-ended federal financing for relief from Medicaid's current restrictions on the types of services that could be provided to persons with developmental disabilities. A new set of federal mandates would be substituted for current Medicaid requirements; the federal oversight role would be recast without necessarily becoming less intrusive.

In general, the ASPE/HHS proposal contains many elements that are worthy of consideration. At the same time, it is far from certain that this proposal's advantages outweigh its disadvantages.

C. Description of the ASPE/HHS Proposal

The ASPE/HHS proposal contained three principal elements. The first element is the replacement of open-ended Medicaid financing with an indexed formula-grant funding mechanism to distribute federal aid to the states for specialized DD services. The second key element is a proposal to entitle certain individuals to a minimum array of services. The final element creates a new framework for federal oversight of federally-financed state/local services to persons with developmental disabilities. Before discussing these elements, it should be pointed out that the available draft materials do not contain specific proposals in these areas - only as a description of broad concepts and working principles.

1. ASPE/HHS Working Group's Financing Mechanism. The most noteworthy feature of the ASPE proposal is its plan to radically reorganize federal financing of specialized DD services. As noted above, the proposal would terminate Medicaid's role as the principal federal financing vehicle for specialized DD long-term care services. In its place would be substituted an indexed formula-grant program under which federal assistance would be distributed to the states on behalf of persons with developmental disabilities. A state's formula grant allocation would be based on its current level of federal Medicaid earnings, adjusted annually according to changes in prices and population; certain states also would receive an "equalization payment." More specifically:

Both the ICF/MR and home and community-based waiver programs for persons with developmental disabilities would be eliminated as components of the Medicaid program. In addition, the use of Medicaid financing for personal care, daytime services, and intermediate nursing facility services on behalf of persons with developmental disabilities also would be ended.

- The current amount of federal Medicaid outlays in the foregoing categories would be shifted to a state grant program established under a newly created statutory authority in the Social Security Act that would be separated entirely from Title XIX. Under this grant program, a state would be "held-harmless" at its current level of Medicaid funding for the foregoing services.

Following the establishment of its base funding level, a state's grant allocation would be increased by a formula that reflected the combined increases in the costs of services with changes in the number of severely disabled persons (general population change would be used as a proxy). Projections developed by ASPE/HHS consultants indicate that the base allocation of each state under this index would increase at a rate of six to seven percent annually over the next four-five years.

A separate pool of funds would be established for allocations to those states that currently utilize Medicaid dollars to support specialized DD services at a level less than the national average (defined as state/federal Medicaid spending per person, where total spending is the numerator and the total U.S. population is the denominator). [N.B., For present purposes, this average is termed the "per capita spending base"; this base should not be confused with average spending per person receiving services.] As initially conceived, this separate pool of funds would have represented a one-time, fixed sum of \$250 million. These pooled funds would have been distributed to states with per capita spending bases below the national average; each affected state would have received a special allocation that was inversely related to the difference between its per capita spending base and the national average for all states. In other words, states with the lowest per capita levels of Medicaid reimbursement for specialized MR/DD services would receive proportionately more of the \$250 million equalization pool than "low spending" states which had per capita base spending levels nearer the national average. After this one time adjustment, no further adjustments in the expenditure base would have been made and allocations to states in future years would have been regulated solely by changes in the rate of inflation and population.

During the summer of 1988, the ASPE/HHS Working Group tested a second "state equalization" approach. Under this "budget neutral" option, total federal assistance to the states would be adjusted in accordance with the recent historic rate of increase in Medicaid spending for specialized DD long-term care services. The equalization pool, thus, would be a permanent feature of the funding mechanism. Rather than providing a one-time appropriation to equalize the distribution of federal funds, the budget neutral option would regulate federal assistance in the following way:

- the overall level of federal aid would be regulated by the projected rate of increase in federal Medicaid outlays under current law; and,

- after adjusting state base allocations for inflation and population change, the difference between the total level of authorized federal outlays and the amount required to fund each state's base allocation would be distributed to states with relatively low levels of current Medicaid spending, again in inverse relationship to their position with respect to the national average.

As will be discussed in more detail below, there are substantial differences, over the long term, in the effects of these two methods of allocating grant funds.

Receipt of federal grant assistance would be conditioned upon a state's documenting that qualifying expenditures would be made on behalf of persons with developmental disabilities. The proposal is predicated on the provision of such documentation through a dedicated claims processing system.

Like the Chafee/Florio legislation, state expenditures on behalf of persons with developmental disabilities would be subject to a

"maintenance of effort" requirement. Unlike Chafee/Florio, however, a state's level of fiscal effort apparently would not be subject to periodic adjustment to take into account the effects of inflation.

As noted above, there are substantial differences between the two alternative grant allocation schemes considered in developing the ASPE/HHS proposal. These differences affect both the total level of federal outlays as well as the relative amounts of federal assistance that would be distributed to particular states.

Under the originally proposed method of regulating total federal spending and determining individual state allocations (i.e., providing a one-time adjustment in allocations to narrow the relative differences in federal payments among the states), the following would occur:

In the first year, federal spending would actually exceed the levels forecast under current law by \$250 million. This "excess" amount would be distributed to those states which had levels of federal/state Medicaid spending below the national average. Rather than the 9.2 percent increase in expenditures projected by ASPE/HHS under current law, a 15.3 percent increase would be authorized in the first year of the program. By the second year, the total amount of federal assistance distributed under the formula grant would be approximately equal to the amount projected under current law. This occurs because HHS/APSE assumed that inflation plus population growth would total only 3.6 percent. By the third year, total federal assistance under this approach would be 9.5 percent (approximately \$430 million) below projections under current law. In contrast to the budget neutral option that ultimately formed the basis for HHS's initial FY 1990 budget submittal, the original option can be viewed as trading-off a one-time increase in federal assistance for a substantially lower rate of growth in future federal support. Under the budget neutral option, total federal outlays would not change from the levels predicted under current law (although it also is important to understand that outlays would not increase in excess of such levels either).

With respect to the allocations received by individual states under either option, future increases in federal support in those states where total state/federal Medicaid spending on behalf of persons with developmental disabilities was above the national per capita spending base would be tied solely to increases in population and inflation. As noted above, the ASPE/HHS Working Group assumed that the projected level of change in those two variables would be about 3.6%. The rate of projected increase, of course, is dependent on one's assumptions about future inflation rates and population growth. States below the national average would face very different circumstances, depending on which funding "equalization" option was employed. Under either option, such states would receive additional federal assistance. If the fixed, \$250 million appropriation was used, however, the adjustment would be a one-time only change. Clearly, \$250 million would fall well short of the number of dollars that would be necessary to achieve parity among the states with respect to the national per capita base expenditure average. Low average states, therefore, would be permanently locked into federal grant levels below the national average even with the proposed special "catch-up" allocation.

Under the budget neutral option, over time low average states would have a better opportunity to receive disproportionate increases in their grant allocations and, hence, a higher level of parity among the states would be achieved. At the same time, the following consequences of this apparently laudable objective of equalizing payments among the states need to be recognized:

First, states with higher average rates of expenditure would be subject to a decidedly lower rate of increase in federal aid than they might expect under current law.

- Second, the period of time required to achieve parity, in all probability, would be relatively extended.

Third, should the national inflation rate increase dramatically, the amount of dollars available to distribute to low average states would be reduced since the ASPE/HHS proposal would fix, in statute, the allowable level of total federal expenditures over a five-year period. High rates of inflation would draw more dollars from this fixed-sum appropriation to meet base allocation adjustment requirements and, hence, leave fewer dollars available for the purpose of equalization.

In selecting the "budget neutral" option, the ASPE/HHS Working Group evidently reached the conclusion that there would be little support for any proposal which, within a period of two-three years, would result in a net reduction of federal outlays on behalf of persons with developmental disabilities when measured against outlays that would be projected under current law. While the "budget neutral" option would avoid this outcome, it is important to point out that this approach would have the following results:

- (a) the level of federal assistance would be limited to a fixed federal appropriation level, regardless of the demand for or cost of services furnished to persons with developmental disabilities;
- (b) unlike the Medicaid program, a state could not expand its program services (and, consequently, its spending) significantly and expect a proportionate increase in federal assistance; and,
- (c) federal assistance would be redistributed from states which have relatively higher levels of Medicaid support for specialized DD services to states with relatively lower levels of such support.

The shift from Medicaid financing of services to a formula-grant program, as proposed in the ASPE/HHS plan, would constitute a major change in federal policy. The open-ended funding associated with the Medicaid program results in increased federal financial participation whenever a state's expenditures for Title XIX-reimbursable services rise. The total amount of federal aid a state can receive, then, is tied to the extent a state is willing to sponsor services that qualify for Medicaid funding. Under a formula grant mechanism, however, the amount of federal aid would be regulated mainly by exogenous variables: that is, factors such as inflation, population growth, and a state's position relative to all states with respect to average per capita Medicaid spending, rather than the level of a state's spending on services.

By introducing an interstate funding equalization factor into its proposed allocation methodology, the ASPE/HHS Working Group's plan attempts to address the potential objections of states that have not employed Medicaid dollars extensively to finance specialized DD services (for whatever reason). The equalization factor also is intended to serve the broader purpose of promoting access to needed services by similarly situated persons with severe developmental disabilities, regardless of where they may reside.

Entitlements. While the revision in federal financing of specialized DD services described above would represent a sweeping change in its own right, a second policy shift proposed by the ASPE/HHS Working Group also would have far-reaching consequences. The reform proposal would require each state to agree to entitle all persons who are severely or profoundly mentally retarded (or have a related condition and function at a level similar to that of a severely or profoundly mentally retarded person) to a core set of services consisting of: (a) case management; (b) respite care; (c) residential services; and, (d) "developmental/vocational services." The framers of the proposal argue that persons with more severe disabilities should be the focal point of federal assistance for persons with developmental disabilities. In addition to designating this population as the "entitled" target group, the ASPE/HHS proposal also intends to make a basic "safety net" of critical services available to such individuals. The following points are worth noting about this aspect of the proposal:

By the Working Group's reckoning, approximately 450,000 persons, nationwide, would fall within this entitled target population (270,000 adults and 180,000 children). By comparison, about 175,000 persons today receive specialized Medicaid-funded DD services under the ICF/MR and HCB waiver programs. The Working Group's analysis discounts the potential impacts of this expanded, federally-mandated service population by pointing out that: (a) the needs of most children are met via special education programs; and (b) most states have widened the range and scope of services available to adults with mental retardation and other related conditions so substantially that they would not be required to expand existing services and expenditures significantly to meet the proposed new federal mandate.

The Working Group's target population is far narrower than the one proposed in the Chafee/Florio legislation. Even if we ignore the potential effects of gradually increasing the age of onset of a qualifying disability, roughly 750,000 persons would become eligible under S.1673/H.R.3454, solely based on the receipt of SSI benefits and the presence of mental retardation or another related condition. The selection of broader financial eligibility criteria by a state, as permitted under the Chafee/Florio bill, could increase the number of eligible persons to well over one million. Consequently, while the entitled population under the ASPE proposal is broader than the number of persons currently receiving specialized, Medicaid-financed services, it is substantially narrower than that targeted under the Chafee/Florio legislation.

While detailed legislative specifications are not available, the ASPE/HHS proposal outlines what appear to be standard means of determining whether a person falls within the target population. The determination of a persons eligibility would be tied to the utilization of federally-approved assessment instruments.

- Eligibility for federally-assisted services would not be linked in any way to eligibility for Medicaid benefits or receipt SSI/OASDI income assistance payments under the Working Group's proposal.

Since eligibility would depend solely on the level of an individual's disability, some thorny issues currently involved in achieving Medicaid coverage of certain persons (e.g., children living at home) would become moot.

The Working Group proposed that states be required to furnish a minimum array of services that varies markedly from those proposed in the Chafee/Florio legislation. While case management is a common element of both proposals, the ASPE/HHS proposal would limit the mandated array of in-home services to respite care while entitling eligible recipients to both residential services and an expanded array of daytime services. S.1673/H.R.3454 would limit the types of daytime services that would have to be made available to all persons to "specialized vocational" (prevocational and supported employment) services, require states to offer a broad array of in-home services, and mandate that "protective intervention services" be made available to all eligible persons. The Chafee/Florio legislation would not mandate that residential services be furnished to all eligible individuals. Given these differences, if we use the states' recent experience as a guide, the minimum service array proposed by the Working Group could be far more costly to furnish than the services that would be required under S.1673/H.R.3454.

Under the ASPE/HHS proposal, states could decide to utilize the dollars available through its federal grant allocation to serve other persons with developmental disabilities who fall outside the entitled target population (e.g., persons with mild to moderate developmental disorders). Presumably, however, a state also could limit the number of persons served and restrict the types of services that would be made available to them. Again, the ASPE/HHS proposal is not clear on this point.

While the Working Group proposed a shift to a disability basis of determining eligibility to receive federally-financed specialized DD services, the proposal does not entirely ignore the issue of client/family resources. Under the tentative proposal, individuals or families would be expected to contribute unspecified amounts to meet the cost of services, depending on their economic circumstances. It is important to recognize, however, that a requirement that individuals or families contribute to the cost of services is a significantly different approach than utilizing income as a factor in determining the applicant's/recipient's eligibility.

Persons receiving services would continue to be eligible for "generic" state-federal benefit programs, including Medicaid, income assistance, and food stamps, but only if they met the same eligibility standards as other low income persons in the state. In cases where a person has gained eligibility for Medicaid through the application of a special income test applicable to institutional residents (as is the case in the majority of state HCB waiver programs), eligibility for Medicaid benefits would be lost under this proposal.

States also would be permitted to include other services within their programs. Beyond a prohibition against duplication of benefits/services that are funded under other federal programs (particular, special education), states would have the latitude to select additional services that it wished to offer, over and above the mandated array of services.

In summary, then, the ASPE/HHS proposal would create an affirmative entitlement that certain persons with developmental disabilities receive selected services, as appropriate. States could elect to serve other persons or add additional services. This approach contrasts sharply with the Chafee/Florio legislation which would entitle a broader population to a somewhat less intensive array of services.

The Working Group's proposal is predicated on the notion that access to specialized DD services supported in part by the federal government should be principally based on the severity of a person's disability, rather than such factors as the individual's income, where the person resides, or variations in state policies affecting Medicaid eligibility. In suggesting that a minimum array of services be mandated, the proposal attempts to describe the types of services which typically would be required by persons who are more severely disabled. The clear objective of this proposal is to alter current federal policies in order to ensure that, on a nationwide basis, all similarly situated individuals with severe developmental disabilities enjoy equal access to services. In contrast, Medicaid policy in general was characterized by the ASPE Working Group as: (a) biased against the provision of in-home services; (b) promoting significant coverage gaps; and, (c) subject to inconsistent implementation among the states.

The potential implications of this element of the Working Group's Medicaid reform proposal are discussed in more detail later in this paper.

3. Federal Oversight and Other Areas. Beyond these two principal features of the ASPE/HHS plan, there are other elements of the proposal that merit discussion. In particular, these elements are: (a) federal oversight of the services provided or purchased by a state; and, (b) program administration at the state and federal levels.

- a. Federal Oversight Activities. While states would have flexibility to select the services to be provided (including defining more specifically the minimum core services they would be required to furnish to target population members), the Working Group proposed that the federal government play a substantial role in assuring that the services furnished meet what are described as "federal core standards." Such core standards would be developed to cover the following areas:

- "client rights and protection, including individual case management;
- comprehensive functional assessment using a Federally approved system comprised of a series of empirically derived assessment tools;
- individual program plans with behaviorally stated objectives;
- a uniform performance accounting system; clearly delineated responsibilities of providers serving the individual;
- a process for monitoring and revising client programs; and
- minimum health, safety, and sanitation rules."

While the ASPE/HHS plan did not (and, apparently, still does not) detail the precise nature and intended scope of these "federal core standards," the framers of the proposal noted that they would constitute a "...quality assurance system [that] would focus on the client rather than on providers of service."

Under the Working Group's proposal, state and federal responsibilities for quality assurance would be organized as follows:

At the state level, the ASPE/HHS Working Group recommended that all program licensure/certification activities be assigned to an agency independent of the agency which is responsible for the direct management of programs financed with federal grant funds. Such an arrangement was viewed by the Working Group as a better approach to assuring that high quality services would be provided. In a somewhat related vein, the proposal also called for "open enrollment" of qualified vendors in order to promote access to services.

At the national level, the federal administering agency would be required to conduct "on-site reviews" of services financed with formula grant funds in each state to assure that such services were furnished in accordance with the "federal core standards." The Working Group characterized the purpose of these on-site reviews as similar to federal "look-behind" surveys of ICF/MRs. While the ASPE/HHS report notes that a less active federal oversight role could be defined (potentially through the use of "deemed" status for facilities accredited by such national accrediting bodies as ACDD), it contended that "...the ultimate power to exercise sanctions should increase proportionately with the degree of flexibility given to the States. This approach will ensure an appropriate level of Federal Government responsibility in protection of program clients."

These quality assurance elements of the proposal are difficult to interpret since only very sketchy specifications are provided regarding the range, scope, and detail of the various elements that would constitute the federal core standards. Despite the acknowledgment of the principle that standards should be "client-oriented," there is little in the proposed scope of the core standards that appears to differ markedly from the areas covered in current federal ICF/MR regulations, which themselves have been portrayed by HCFA officials as "outcome-oriented" (a characterization many would dispute). Also it is unclear from the available materials whether such standards would permit a state to develop and enforce additional standards that it viewed as appropriate. The degree to which the federal core standards would be prescriptive also is unclear. Obviously, however, the proposal is not intended to result in any lessening in the present level of federal oversight of programs. Indeed, it seems reasonable to conclude that the ASPE/HHS plan would broaden the federal government's role in regulating state/local programs.

It should be noted that language in Representative Waxman's bill (H.R.5233) employs language drawn from the HHS/ASPE proposal to describe the features of a quality assurance system the Secretary of HHS would be required to put into place to regulate "community habilitation services", which, under the terms of H.R.5233, would be added as an optional state Medicaid plan coverage (see Appendix B).

- b. Administration of Programs. Under the ASPE/HHS plan, state administration of specialized, federally-financed DD services would be consolidated under a single agency (with the exception of licensing activities, as noted above). The termination of Medicaid's role in funding services, therefore, would permit a state to resolve the complications currently posed by the role of the single state Medicaid agency in administering services.

At the federal level, the proposal calls for administration of the program to be transferred from HCFA to another unit of HHS. The Office Of Human Development Services was viewed by the Working Group as the most logical choice.

As noted earlier, the proposal also would require each state to operate a "claims processing" system. In addition, states would be required to collect certain specified service data and report it to the federal government. The proposal, however, includes no specific provisions regarding payments to the states for the costs of program administration.

In its present form, the ASPE/HHS proposal does not establish a requirement similar to the Chafee/Florio legislation that a state develop an "implementation strategy" describing the steps to be taken to effectuate the transition from one financing system to another. In addition, the proposal does not discuss strategies for the transition of federal responsibilities from Title XIX to a new statutory framework. For example, the Working Group's report offers no clues as to whether the development of federal "core" quality assurance standards is intended to proceed implementation or whether present federal regulations would remain in place until such standards could be developed and promulgated. Also, no process is mentioned for gaining input at the state or the federal levels concerning proposed changes.

4. Summary. In general, the ASPE/HHS proposal is based upon an assessment that present reliance on Medicaid as the primary federal vehicle for funding specialized DD services is ultimately counterproductive as far as achieving high quality services for individuals with developmental disabilities in a cost effective manner. To address this issue, the Working Group's proposal envisions changing the entire mechanism for financing such services, by eliminating Medicaid's current role in funding such services and substituting a new formula-grant mechanism. To ensure that federal dollars are targeted to persons most in need, all states would be required to serve individuals who are "severely or profoundly" disabled, regardless of income. The proposal calls for a reorganization of the management of service systems while anticipating a strong affirmative role for the federal government in the oversight of programs.

D. Commentary on the Proposal

This proposal is based on the notion that a radical change is needed in the structure of federal assistance furnished to the states on behalf of persons with developmental disabilities. Severing funding of specialized DD services from the Medicaid program certainly would represent a sweeping change. The principle aim of the Department's Working Group was to correct the institutional bias that has characterized Medicaid financing of specialized DD services and solve other problems that have arisen when Medicaid dollars are used to finance DD services. The proposal is based on the premise that the institutional bias of the Medicaid program promotes inefficiency in service delivery. By permitting federal dollars to be used to finance a wider variety of services and centering eligibility on an individual's level of disability, rather than the less defensible test of "need for institutionalization," the proposal seeks to respond to long-standing criticisms of the Medicaid program.

The proposal also is premised on the notion that specialized DD services, which are based on the provision of habitation and social support services, are fundamentally at odds with the basic, historical role of the Medicaid program: namely, to provide a means of meeting the health care needs of low-income Americans. Finally, the proposal is designed to contain the future rate of increase in federal outlays for specialized DD services, by radically revamping the method of funding services.

While the HHS/ASPE plan obviously is designed to cure many of the oft-cited defects of current policy, it is important to examine critically the proposal's potential ramifications for financing and managing specialized DD services. It has many similarities to the proposals

that emerged early in the Reagan Administration, which offered to substitute "block grant" funding mechanisms for a more variety of categorical federal programs. These proposals promised to grant states greater flexibility in the use of federal dollars in exchange for a slower rate of growth in federal funding or reduced federal support. The rationale offered by Reagan Administration spokespersons was that, with greater flexibility, states could operate programs more efficiently and, hence, make better use of federal assistance. In addition, states could better integrate federal and state programs and, thereby, address state and local concerns more appropriately and effectively.

It is difficult, however, to characterize the ASPE/HHS plan as a block grant proposal, since it would impose very specific requirements on the states regarding the classes of individuals they would have to serve and the services that would have to be made available to such persons. In addition, the plan clearly does not envision a withdrawal of federal regulation and oversight of state/local activities. It is not clear whether the states would be permitted to exercise greater control over the use of federal dollars in delivering specialized DD services. Indeed, the tone of the proposal indicates that its authors believe there is a strong, ongoing need for federal oversight because, left to their own devices, the states might not respond appropriately to the needs of severely disabled individuals or might tolerate the provision of sub-standard services.

Given the fact federal oversight and service delivery dictates would not be reduced in exchange for new restrictions on the level of federal funding, the question is would the HHS/ASPE plan create a better framework for serving persons with developmental disabilities than current federal policies. The answer to that question is by no means clear.

From the standpoint of federal financing of specialized DD services, the following observations concerning the proposed funding mechanism are in order:

Under the best case scenario (i.e., the "budget neutral" option), states, in the aggregate, would receive the same number of dollars as they would under current law. If the Administration's original grant formula were used (i.e., regulating total spending by inflation plus population growth following a one-time equalization adjustment for low-spending states), the rate of increase in federal spending for specialized DD services would be reduced.

Under either scenario, the number of persons the states would be required to serve would be significantly larger than the number of persons currently receiving Medicaid-financed services. Given the fact that no more (and potentially fewer) federal dollars would be available to the states, the basic question regarding the ASPE/HHS proposal is whether most states could be expected to provide the mandated services to the entitled population without other individuals losing services or states having to increase their own spending substantially.

While it is impossible to provide unequivocal answers these questions, it seems obvious that: (a) many states would have to expand services in order to comply with the entitlement provisions of the legislation; and, (b) any increased management latitude the states may gain is unlikely to allow them to achieve enough efficiencies to keep their budgets in balance while expanding services.

Ultimately, the viability of ASPE/HHS's plan depends on whether present Medicaid policies create such tremendous inefficiencies that removal of the financing of such services from the Medicaid program would result in substantial savings that could be used to expand services sharply. The fact that existing service delivery systems could not be totally reconfigured overnight argues against such a fiscal dividend in the short-run. In the long-run, the potential for such a dividend depends almost entirely on how the proposed federal "core" standards would be structured. There is little in the ASPE/HHS proposal to indicate that such standards would be any less

proscriptive than present federal standards. If that is the case, any greater flexibility obtained by the states might be largely illusory.

In addition, although future inflationary increases would be tied to the general price index, there is no evidence that service costs would follow the general rate of inflation. If they did not, then one critical effect of the funding formula would be to increase the states' share of operating costs. While the Working Group explored the development of an alternative index that would be more sensitive to the costs of delivering specialized DD services, no index would be as reliable as the present Medicaid program in assuring that increases in service costs would be shared equitably between a state and the federal government. In addition, no indexing mechanism that relies on exogenously defined variables would deal with the significant, unpredictable changes that might occur (e.g., Congressional action to change the federal minimum wage) or with the equally unpredictable fiscal outcomes of the promulgation of new federal regulations. On the whole, this element of the formula could prove to be extremely problematic for the states.

In contrast to the Medicaid program, where increases in program spending and the rising costs of services are at least partially reimbursed by federal Title XIX payments, the mechanism proposed by the ASPE/HHS Working Group would shift the entire fiscal risk associated with increases in program costs to the states. It is important to point out that, based on the information provided in the ASPE proposal, it is virtually impossible for any state to gauge the level of such risk.

It also is important to point out that the Working Group's proposed method of equalizing funding among the states is far from an ideal solution. First, equalization would be achieved (under the budget neutral option) only over an extended period of time; at the same time, all states would face the same program requirements. Under the original proposed grant formula, only one, very limited attempt would be made to equalize state allocations.

Second, the proposed mechanism suffers from the drawbacks associated with using any single variable to equalize spending differences among the states. By relying on per capita Medicaid expenditures to regulate equalization, the formula ignores such factors as interstate variations in the costs of delivering similar services. The mechanism also is based on the assumption that states with fairly high Medicaid spending levels receive "enough" federal support. To be generous, this is an heroic assumption.

Finally, while the need to narrow interstate variations in federal support is a valid concern, it must be recognized that equalization would be achieved over the long-term by redistributing federal dollars from states which currently are more reliant on Medicaid dollars to "low Medicaid spending" states. It is debatable whether such a reallocation of federal assistance would improve access to services.

In essence, then, the ASPE/HHS proposal asks the states to exchange a medium-risk, open-ended source of financing for a funding mechanism that is closed-end and poses high fiscal risk. From the perspective of the states, the degree of risk associated with the ASPE/HHS proposal is tied directly to the extent to which the cost of complying with "federal core standards" increase, rather than diminish

An extremely important aspect of the ASPE/HHS proposal is the statutory provisions governing the award of grants to the states. Without strong safeguards, the states might find that the overall level of federal aid would be reduced at some future date in order to trim the federal deficit. Currently, Medicaid payments to the states are exempt from any automatic funding reductions that are triggered by the Gramm-Rudman-Hollings deficit reduction

mechanism. The ASPE/HHS report does not address this question. In addition, it does not describe the approach that would be employed to prevent either the Administration or Congress from tinkering with the funding mechanism to reduce outlays in subsequent years. Hence, there is some uncertainty whether federal assistance levels would be assured. States, therefore, could find themselves faced with problems similar to those experienced in other federal programs when Congressional appropriations were reduced or held constant over time while federal requirements were left unchanged or even increased.

Beyond these fiscal uncertainties, the proposal's federal oversight requirements could pose major problems for the states. A very strong oversight role, including possibly the promulgation of peremptory federal standards, would constitute a significant change in the management of MR/DD programs. Historically, states have exercised considerable control over the scope and range of services furnished to persons with developmental disabilities. Under the ASPE/HHS proposal, federal requirements governing client eligibility and service delivery standards would significantly reduce the ability of a state to manage its service delivery system on its own terms. While the growing use of Medicaid as a means of financing specialized DD services has resulted in increased federal involvement in the delivery of services, ASPE/HHS's proposal ironically would broaden federal involvement without adding further federal resources (and, potentially, reducing the rate of growth in such resources).

In addition, the ASPE/HHS proposal presumes that the development and implementation of federal standards would result in improved services to persons with developmental disabilities. In the absence of specific proposals in this area, however, it is impossible to judge whether that would be the case or not. Indeed, substantial arguments can be made that peremptory federal standards would serve as a barrier to improving the effectiveness of services.

In addition, it is doubtful that there is broad agreement with another premise of the ASPE/HHS proposal: namely, that the federal role in supporting services to persons with developmental disabilities should begin and end with individuals who are severely to profoundly disabled. While many factors (including federal regulatory policies) may be forcing states to focus scarce resources on such persons, drawing such a line of federal interest in Americans with developmental disabilities would be widely regarded as inappropriate.

The questions raised concerning the funding mechanism proposed by ASPE as well as the potential expansion of federal standard setting and oversight roles are extremely problematic. Until further specifications are available, the ASPE/HHS proposal will remain very difficult to evaluate. While persuasive arguments can be advanced for decoupling specialized DD services from the Medicaid program, it is difficult to consider such benefits a fair exchange for the loss of open-ended federal funding of services until critical unanswered questions are resolved.

E. ASPE's Other Reform Options

While not discussed in detail in the ASPE/HHS report, it is useful to note the alternatives to the above proposal considered by the HHS/APSE Working Group. Should financing of specialized DD services remain within the Medicaid program, the Working Group proposed that the following steps be taken:

- **ICF/MR Eligibility.** Steps should be taken to limit the provision of ICF/MR services to persons who are severely to profoundly disabled. ASPE/HHS also proposed that the admission of children to ICF/MRs be curtailed and that use of large facilities be restricted. While noting that the addition of further restrictions on ICF/MR admissions would reduce federal outlays, the Working Group also supported a broadening of federal funding of home and community-based services so that the fiscal impact of limiting ICF/MR admissions would be neutral.

Nursing Home Placements. Policies should be instituted to restrict the use of nursing facilities as a placement option for persons with developmental disabilities.

Payments. The existing variance in Medicaid payments to the states for long-term care services should be examined, including experimentation with "client-centered" payment systems.

Quality Assurance. National accreditation standards should be granted "deemed status" - Le., recognized as the equivalent of existing ICF/MR survey procedures.

Parental Responsibility. Changes in federal statutes should be considered to permit parents of persons with developmental disabilities to be charged a portion of the costs of furnishing services to their disabled sons and daughters.

These "alternatives" obviously are not as sweeping in scope as the principal ASPE/HHS proposal.

F. Conclusion

The ASPE/HHS Working Group's report is interesting, primarily because it concludes that federal financial support for long term care support for persons with developmental disabilities should be detached from the Medicaid program. The report advocates the development of an entirely new federal program of financing and overseeing the provision of such service. This program would replace Medicaid as the principal vehicle for funding services to persons with developmental disabilities. While this proposal serves as an interesting counterpoint to other Medicaid reform proposals, several basic issues would need to be resolved before such a radical change could be seriously entertained by various groups interested in curing the ills presently associated with Medicaid policies.

APPENDIX D:

THE SECTION 1915(D) WAIVER AUTHORITY

APPENDIX D:

THE SECTION 1915(D) WAIVER AUTHORITY

While not viewed as a "Medicaid reform" proposal *per se*, the creation of a new home and community-based waiver authority, similar to Section 1915(d) of the Social Security Act, is an option worthy of examination. It would represent an "incrementalist" step toward addressing limitations imposed by present federal policies governing the management of waiver programs. In addition, by assessing the merits of this option, we will be able to explore the potential advantages and disadvantages of approaching Medicaid reform by employing mathematical formulae to constrict the potential fiscal impacts of changes in Title XIX policies.

A. Background

Congress enacted the Section 1915(d) HCB waiver authority at the behest of the State of Oregon, which contended that, if it were given broad flexibility to manage Medicaid long-term care expenditures on behalf of elderly persons, it would be able to operate under an indexed rate of growth in federal Medicaid payments for long-term care services. Congress accepted the State's contention that it should be afforded the opportunity to manage all long-term care expenditures on a unified basis in order to meet its objective of avoiding the institutionalization of elderly persons (although with a lower annual indexing factor than proposed by the State).

In large part, Oregon's proposal stemmed from HCFA's administrative policies governing the Section 1915(c) HCB waiver authority. In particular, acceptance by a state of a limitation on the number of HCB waiver participants in exchange for HCFA approval of a state's waiver request limited the ability of state officials to recapture the full savings that might be associated with reduced reliance on nursing facilities. Indeed, under a Section 1915(c) waiver, any savings that results from more cost-effective, community-based alternatives to nursing facility services are returned to the federal government, rather than becoming available to fund services to a growing population of elderly persons in need of long term assistance and care. In essence, the 1915(d) HCB waiver authority eliminates this problem by permitting a state to recapture all savings and apply them toward meeting the needs of persons not already receiving long-term care services. Oregon officials argued that, given this flexibility, they could deinstitutionalize or deflect from nursing facility placement a sufficient number of elderly persons to increase the overall cost effectiveness of long-term care spending in the State (i.e., the same number of dollars would support services to more individuals).

While the Reagan Administration opposed passage of the Section 1915(d) (principally due to concerns that a larger number of individuals would become eligible to receive generic Medicaid benefits), Congress nonetheless added this new waiver authority to the Act. In 1988, Congress amended Section 1915(d) to modify the method of calculating the expenditure base against which overall state long-term care expenditures would be calculated, essentially by authorizing the use of the most recent expenditure data available in calculating the expenditure base at the time a state selects the Section 1915(d) HCB waiver option.

Despite reluctance by HCFA officials to allow Oregon to utilize this new authority, the State has preceded to use it. Thus far, however, no other states have elected to apply for Section 1915(d) waivers.

B. Description of the Section 1915(d) Waiver Authority

The simplest description of the Section 1915(d) waiver authority is that it permits a state to manage Medicaid-reimbursable long-term care expenditures as a single source of financing, including expenditures for both HCB waiver and institutional services furnished on behalf of elderly individuals. Apart from establishing an overall limitation on total federal Medicaid payments for long-term care services, Section 1915(d) does not alter the requirements governing the provision of HCB services, as stipulated in Section 1915(c) of the Social Security Act; nor, are requirements applicable to the provision of other Medicaid-reimbursable long-term care services (e.g., nursing facility services) modified in any way. In other words, a state selecting the Section 1915(d) HCB waiver option receives no regulatory relief other than the fact that it is not faced with a limitation on the utilization of Medicaid-reimbursable long-term care services as it presently is under a Section 1915 (c) waiver.

The key provisions of Section 1915(d) of the Social Security Act are as follows:

State Selection. A Section 1915(d) waiver is an additional option available to a state (i.e., it is not mandatory). Furthermore, once a state has elected this option, it may decide at any future date to opt out of the program.

Services Covered. In selecting the Section 1915(d) option, a state agrees to accept a limitation on total long-term care spending for HCB waiver services on behalf of elderly persons, including spending authorized under a Section 1915(c) waiver, SNF and ICF expenditures, and expenditures for certain related long-term services (e.g., personal care and private duty nursing). The types of HCB services upon which a state may expend Medicaid long-term care dollars are no different than those already authorized under the other relevant provisions of the Social Security Act. Section 1915(d) of the Act does not create any new categories of services.

Other Related Provisions. In applying for authorization to manage long-term care spending under the Section 1915(d) waiver authority, a state must make "assurances" that parallel the assurances provided under a Section 1915(c) waiver request, except that a state is not required to make an assurance regarding cost effectiveness. An overall limitation on federal payments to a state is substituted for HCFA's current methods of limiting waiver utilization and expenditures. However, eligibility for long-term care services, including the demonstration that a person would otherwise be institutionalized except for the provision of HCB services, is not altered under Section 1915(d) authority.

- **Secretarial Approval.** By implication, Congress limited the role of the Secretary in approving requests to employ the Section 1915(d) authority to only the non-financial elements of a state's waiver request.

Limitation on Federal Payments. As originally enacted, the limitation on federal payments to a state electing to use the Section 1915(d) authority were calculated by establishing an expenditure base equal to spending for Medicaid-reimbursable services in the year immediately prior to the enactment of Section 1915(d). The limitation applicable to any year in which a state employed the Section 1915(d) authority would be calculated by applying a composite index consisting of a "market basket" measure of the rate of change in the costs of furnishing long-term care services and the change in the number of individuals in a state who were age 75 or older. The legislation set 7 percent as the minimum annual level of increase in federal financial participation but allowed for increases above that level, based on changes in the components of the composite index. In the Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360), Congress amended Section 1915(d) to provide that the base year could be established on a more current basis, thus correcting a technical problem in utilizing

- outdated expenditure data upon which to base the calculation of the limitation on federal payments for long-term care services.

As noted earlier, the Section 1915(d) authority is only applicable for long-term care services furnished to persons age 65 or older.

C. Implications for MR/DD Long-Term Care Services

At least on the surface, the notion of managing all Medicaid-reimbursable long-term care services within a single federal payment category is appealing. Clearly, the creation of a parallel authority to Section 1915(d) for Medicaid-reimbursable long-term care services to persons with developmental disabilities would be beneficial to a number of states, at least in comparison to the present Section 1915(c) waiver authority. In particular:

The removal of the cap on the number of participants would counteract the present disincentives under the Section 1915(c) authority to the use of relatively low-cost services as part of a waiver program. Under the present regulatory waiver formula, a state which attempts to employ waiver funding to support lower cost programs faces the prospect of losing Medicaid financing of services if it does so. Hence, increasingly states are reserving the use of waiver programs for persons who need more intensive services, usually in a specialized residential setting. Thus, HCFA's regulatory cost effectiveness formula contributes to the more general imbalance in the use of Medicaid funding in more expensive out-of-home settings. Under the Section 1915(d) authority, a state potentially could support a more balanced array of services under its HCB waiver program.

Depending on the rate at which the expenditure base is adjusted to establish the federal cap in subsequent years, some states might find an indexing approach far preferable to negotiating expenditure and utilization limits with HCFA. While obviously dependent on a variety of considerations, a state may discover that a relatively generous indexing rate will give it greater ability to access Medicaid funds than negotiating increases in its HCB waiver expenditure cap with HCFA.

Again, in comparison to the regulatory environment that states face today under the Section 1915(c) HCB waiver authority, the creation of an authority like Section 1915(d) could resolve key problems some of the states face in delivering long term care services to persons with developmental disabilities. At the same time, a waiver authority of this type would not address all the problems states encounter under the Section 1915(c) waiver program. In particular:

A state contemplating a major increase in the number of recipients of long-term care services would realize little or no benefit from a Section 1915(d)-like waiver authority. Generally, states which expect the growth in spending to be relatively constrained in the near-term are likely to gain the greatest benefit from such an authority.

- A Section 1915(d) approach could prove to be a risky proposition if the costs of ICF/MR services are unstable. There is no mechanism within Section 1915(d) for adjusting the expenditure base in the event that a state is required to commit more resources in ICF/MR facilities (either public or private) in order to maintain certification.

Finally, the provisions of Section 1915(d) do not recognize the current wide disparity among the states in the use of Medicaid dollars to support long-term care services on behalf of persons with developmental disabilities. Thus, a Section 1915(d) waiver authority would not offer a means by which a state that presently does not utilize Medicaid extensively to support long

term DD service could expect to receive an adjustment in its expenditure base.

Overall, then, Section 1915(d) may provide a precedent for one potential solution to current problems stemming from federal Medicaid policies; however, its utility clearly would be limited to particular circumstances.

In addition, it must be recognized that Section 1915(d) was not designed to grant a state regulatory relief, other than in terms of the number of persons who could receive long-term care services. The authority does not involve a trade-off between regulatory relief and acceptance of a limitation on the rate of increase in Medicaid payments for long-term care services. For example, a state which employed a Section 1915(d)-like waiver authority still would have to gain Secretarial approval for the waivers necessary to offer HCB services. Furthermore, in the context of MR/DD services, no change would occur in the regulatory requirements applicable to ICF/MR facilities or the need to correct any deficiencies in such facilities that might be revealed as the result of federal or state surveys. The determination of eligibility for services would be no different than under present policy (including the requirement that eligibility for HCB waiver services be linked to a person's need for institutionalization). Thus, Section 1915(d) would be best described as a different framework for managing federal Medicaid dollars, rather than as a substantive reform proposal.

In the more general context of Medicaid reform, the foregoing discussion of the Section 1915(d) waiver authority points out that attempting to cure the ills that stem from present policies cannot rely solely on mathematical reformulations of federal payments. While there are persuasive arguments in favor of concocting formula-based payment mechanisms to regulate federal expenditures on behalf of persons with developmental disabilities, such solutions are doomed to fail unless other key areas of policy are addressed concurrently. For example, formula-based payment limits are not the answer to the problems associated with the present instability of ICF/MR costs; such solutions would only exacerbate the impact of rising ICF/MR costs on state budgets. In addition, the thorny issues surrounding the high variability in state utilization of Medicaid dollars can only be imperfectly addressed on a formula basis (as witness by the ASPE/HHS proposal; see Appendix C). Moreover, while utilizing a formula may address some problems that stem from HCFA's practices in administering the HCB waiver program, unless the Secretary's discretion to approve or disapprove waiver requests is somehow modified to provide greater protections for states, many substantive problems will go unresolved.

The foregoing discussion simply reinforces the observation that reforming present federal Medicaid policies as they affect persons with developmental disabilities must be multi-dimensional in its scope.

0. Prognosis

In an early draft of H.R.5233, Representative Waxman's staff incorporated, as one of its proposals for changing current statutes, a parallel to the Section 1915(d) authority. In H.R.5233 as introduced, however, these provisions were deleted, due to the perception by opponents of Medicaid reform legislation that the inclusion of an alternative HCB waiver authority would have some of the same effects as the freeze on institutional payments contained in the Chafee/Florio legislation: namely, the limitation on federal payments would encourage states to withdraw resources from state-operated facilities.

At the request of a number of states, NASMRPD has recommended to Representative Waxman's staff that these provisions be included in a revised version of H.R.5233, scheduled for reintroduction during the 101st Congress. In addition, some states have suggested that the Section 1915(d) formula mechanism, if coupled with the ability of a state to request more broad-scale waivers of certain provisions of the Social Security Act, might represent an important step toward employing Medicaid financing more effectively. At this juncture, however, it is unclear whether a new version of H.R.5233 (or any other forthcoming legislative proposals) will include an option similar to Section 1915(d).

**FEDERAL MEDICAID POLICIES AND
SERVICES TO AMERICANS
WITH DEVELOPMENTAL DISABILITIES:
CRITICAL ISSUES - DIFFICULT CHOICES**